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Understanding the Experience and Multidimensional Needs of Ugandan Patients with Advanced Heart Failure

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PhD

University of Edinburgh

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Submission of PhD

Declaration of authorship

I declare that this thesis is the result of my work and has not whether in the same or different form, been presented to this or any other university in support of an application for any degree than that for which I am now a candidate. I have read and understood the University of Edinburgh guidelines on Plagiarism and declare that this written dissertation is all my own work except where I indicate otherwise by proper use of quotes and references.

Signed

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Date: 9th March 2016

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ABSTRACT

Background: The burden of non-communicable diseases including cardiovascular diseases such as heart failure in Africa is rising rapidly, and they are now recognised as a significant cause of morbidity and mortality in the continent. Heart failure causes significant multidimensional impact (physical, social, psychological and spiritual), even with the advent of medicines that offer mortality benefit. Comprehensive care for heart failure must include palliative care that addresses multidimensional needs in line with patient-centered care. However, most research on heart failure in Africa has not explored these multidimensional needs from the patients' perspective, and palliative care is still seen as being for those with cancer and HIV/AIDS.

Aims: To understand the multidimensional experiences, needs, and use of services by patients with heart failure during their disease trajectory. To understand health care professionals' perceptions of patients' needs, the care required and the availability of services for patients with advanced heart failure in Uganda.

Methods: A total of 48 face to face qualitative longitudinal interviews (36-patient alone, 4 paired-patient and family carer, 8 with bereaved carers), were conducted with 21 patients with stage 3 or 4 heart failure being treated in Mulago Hospital and some of their family carers. Patient interviews were followed by the administration of the African Palliative Care Association African Palliative Outcome Scale supplemented with the broader symptom assessment tool the POS-S. Patients were interviewed during the time of hospitalisation when the researcher first made contact with them, and were followed up monthly by phone. Longitudinal interviews were conducted at 3 and 6 months after the first interview if their clinical condition remained stable, and earlier if there were major concerns or changes in their multidimensional experiences. Eight single interviews were conducted with health professionals (5 doctors, 2 nurses and 1 social worker) involved in the care of the patients. All interviews were audio recorded, and those of the health professionals transcribed verbatim, those of the patients were first translated to English and transcribed and all were exported into QSR Nvivo software version 10 for analysis. Principles from Charmaz's grounded theory (line by line coding, focused coding, constant comparison and theoretical coding) were employed for analysis.

Findings: The patients' experience was that of learning to live with the unknown in a life dominated by symptoms despite, and because of, treatments. The impact of the various symptoms limited physical performance leading to multiple losses. Presence of a high level of health illiteracy, lack of information on their illness coupled with a high reliance on local cultural beliefs to make health decisions, led to the following: delayed recognition of illness and seeking of care; inappropriate self- care and poor adherence to medications; poor understanding of illness and its prognosis; unrealistic expectations of treatment; and inappropriate choices of where to seek care. Patients were often faced with health system challenges that contributed to late diagnosis and exacerbated the problem of poor adherence to treatment because of lack of medicines and lack of information. The illness impact was also observed in the social, psychological and spiritual domains of patients' lives causing anxiety and worry, isolation, rejection and stigma, spiritual pain and spiritual growth. Patients expressed the need for normal functioning, information, to be in control and to be facilitated to cope and adapt to the unknown. Patients employed different mechanisms of coping and adaptation, with hope being central in coping as they tried to live with the unknown. Patients suggested changes to the health system and in the conduct of health professionals to improve future care. Health professionals were able to recognise the multidimensional impact of the illness on the patients, but the details of the concerns tended to differ for the patients and health professionals. Health professionals' proposals on improving care tended to emphasise interventions that would improve physical care as opposed to the other dimensions.

Conclusion: This is the first qualitative longitudinal research in Uganda that has explored the experiences of patients with advanced heart failure to gain an understanding of their needs and concerns from their perspective over the course of their illness. Many concerns such as a lack of information, challenges with coping, the symptom experience and its impact on function and the psychological, social and spiritual aspects of their lives are enduring in literature. However, this study also identified other concerns less common in the literature that could have led to a unique illness experience. These included: health system challenges; the impact of culture; beliefs and poverty; and a high level of health illiteracy.

LAY SUMMARY

Non-infectious diseases such as heart failure cause a lot of ill health and death among those who have them. Additionally, these conditions impact on the psychological, social and spiritual aspects of people's lives even when they are on good treatments. There is therefore, need to incorporate palliative care into the care of those with heart failure in Uganda to address this multidimensional impact. However, for palliative care to be effective these multidimensional needs and impact have to be understood in the patients' social context. Most research on heart failure in Africa has not explored these multi- dimensional needs from patients' perspectives; Palliative care is almost non –existent in heart failure care because palliative care is understood as care suitable for mainly HIV/AIDS and Cancer patients. This study was therefore done to understand these multi-dimensional needs and to identify the gaps in the available services for patients with heart failure so as to improve care.

Methods

Interviews were conducted with advanced heart failure patients sometimes in the presence of their carers if the patients wished for it. These patients were followed up monthly on phone and interviewed every three months for six months to determine changes in their needs over the course of their illness. Interviews were also conducted with health professionals and bereaved carers.

Findings

The patients' experience was that of learning to live with the unknown. Patients' lives were dominated with symptoms. These symptoms limited their daily activities and led to multiple losses. Other findings included:- Presence of a high level of health illiteracy, lack of information on their illness, a high reliance on local cultural beliefs to make health decisions, leading to: delayed recognition of illness and seeking of care; inappropriate self- care and poor adherence to medications; poor understanding of illness and its prognosis; unrealistic expectations of treatment; and an inappropriate choice of where to seek care. Patients were often faced with health system challenges that contributed to late diagnosis and exacerbated the problem of poor compliance to treatment because of lack of medicines and lack of information. The illness impacted their social, psychological and spiritual lives causing anxiety and

worry, isolation, rejection and stigma, spiritual pain and spiritual growth. Patients expressed the need for normal functioning, information, to be in control and to be facilitated to cope and adapt to the unknown. Health professionals were able to recognise the multidimensional impact of the illness on the patients, but the details of the concerns tended to differ for the patients and health professionals.

Conclusion

This is the first research in Uganda that has explored the experiences of patients with advanced heart failure from their perspective. Many concerns such as a lack of information, challenges with coping, the symptom experience and its impact on function and the psychological, social and spiritual aspects of their lives are enduring in literature, however, this study also identified other concerns less common in the literature which could have led to a unique illness experience. These included: health system challenges; the impact of culture; beliefs and poverty; and a high level of health illiteracy.

PROLOGUE AND OVERVIEW OF THE THESIS

This thesis presents and discusses the findings of a study examining the experience and multidimensional needs of Ugandan patients with Advanced Heart Failure (HF). Non-communicable diseases (NCDs) such as HF are becoming increasingly important as causes of morbidity and mortality in the Ugandan population. Records from the Uganda Heart Institute in Mulago Hospital, demonstrate a 500% increase in outpatient attendance due to heart -related conditions from 2005-2009 (Ministry of Health Uganda, Health Systems 20/20 and Makerere University School of Public Health, 2012). The majority of patients with HF in Uganda present with advanced disease and have a high symptom burden with multidimensional needs and, therefore, a poor quality of life (QOL). Most of the treatments that improve mortality in HF are not available or are inconsistently supplied in health centers in Uganda. The course of illness is dominated with repeated hospitalisations significantly impacting the health system. All the above issues highlight the need for integration of palliative care into the management of those with HF in this setting.

This study was therefore inspired by the need to develop palliative care services in Uganda for non-cancer patients, particularly those with advanced HF. My background is as a palliative care doctor in Uganda working in the national referral hospital, and I have been involved in setting up and developing palliative care services in that hospital. I am also involved in training medical students and postgraduate students in palliative care. I have observed that in Uganda most referrals to palliative care services are patients with cancer and or HIV/AIDS and rarely those with organ failure including HF. When HF patients are discharged by hospital palliative care teams, there is loss of continuity of care because home based care services are centred on cancer and HIV/AIDS patients and rarely take on patients with other conditions. Previous literature from high-income countries abounds with evidence on the multidimensional needs in those with HF, however, these are not recognised in our setting and therefore not addressed because of the biomedical approach to treatment and care. The aim of this study was therefore to describe the multidimensional needs and impact of HF on patients in the Ugandan context in order to provide an evidence

base for the improvement of clinical care for these patients and for providing evidence for training and formulating policy on the care of this condition.
Chapter one gives an overview on the burden, causes, current management and outcomes of HF in Sub-Saharan Africa (SSA) with emphasis on Uganda in the context of the imminent NCD epidemic. The envisaged impact of HF (based on previous literature) on the patients and health system is also highlighted. The need for qualitative research to understand the patients' illness experience to identify their multi-dimensional needs and enable planning of care that integrates palliative care has also been described. The chapter concludes with highlighting some of the existing theory of the illness experience that would facilitate understanding of the specific literature on the HF experience in the following chapter.

Chapter two is a review of the literature relating to patients' experience of living and dying of HF as well as their experiences of the health care system. Views of health professionals on how care can be improved are also reported. Most of the literature originated from high-income countries.

Chapter three describes the chosen research design and methods of the study. The rationale for the choice of use of a qualitative research approach and employing the constructivist theoretical framework, principles of grounded theory and in-depth serial interviews is given. Ethical issues in qualitative longitudinal research when dealing with palliative care patients are also discussed.

Chapter four gives a description of the recruitment process, the study participants' demographic and clinical characteristics and how the serial interviews for patients and the one-off interviews for health professionals were conducted. Characteristics of those excluded and those who did not consent are also described.

Chapters five to eight report on the findings of the study based on the study objectives. Chapter five addresses objective one: 'To map patients' experience of being diagnosed with, treated for, living and dying of HF in Uganda'. The experience of patients with HF is described in terms of the three major phases that stood out as critical periods in all patients' accounts of their experiences that is: the journey to

diagnosis; the journey to treatment; and the journey to death. Their experience is also described in terms of the impact of the illness on the daily lives of the patients. Chapter six addresses objective two: 'To map the pattern of patients' needs and concerns over the course of their illness and the factors influencing the changes.' Changes in physical, social, psychological, information and spiritual needs and the concerns of patients over the course of the illness and the factors influencing the changes are described. Chapter seven reports on patients' perceptions of the services that were available to meet their multidimensional needs and how they matched with their need. It addresses two objectives: 'To map services available to patients how they match with need'; and 'To capture from both patients and professionals perspectives on what would constitute better care and how this can be achieved.' Chapter eight reports on health professionals' perspectives on patients' needs, the care required and what would constitute better care. It addresses objective four 'To describe health professionals' understandings of patient needs, care required and service availability,' and part of objective five: 'To capture from both patients' and professionals' perspectives on what would constitute better care and how this can be achieved.'

Chapter nine, the discussion, reflects on the methods used, their strengths and weakness. Findings from chapters four to eight are discussed and compared to previous research and theory on the illness experience and living with HF.

Chapter ten gives conclusions to the study and suggests priorities for improving clinical care, training, health education, policy and future research.

OPERATIONAL DEFINITIONS AND TERMINOLOGY USED:

Advanced heart failure: Patient with any four of the following five criteria:
1) severe symptoms of heart failure with dyspnoea and or fatigue at rest or with minimal exertion (NYHA functional class III or IV).
2) episodes of fluid retention.
3) objective evidence of severe cardiac dysfunction shown by a low Left ventricular ejection fraction<30%
4) severe impairment of functional capacity
5) history of 1 or more episodes of hospitalisation in the past 6 months. Adapted from Metra et al. (2007) definition of advanced heart failure.

Illness experience: The way people define and adjust to perceived interruptions or changes in their health (Ritzer, 2007).

Illness Trajectory: The course of illness over time, plus the actions of clients, families and healthcare professionals to manage that course (Corbin and Strauss, 1991).

Needs: A need is present if there is the capacity to benefit from an intervention (Stevens and Gillam, 1998. Wright, Williams and Wilkinson, 1998). A need may be felt and expressed by a patient but may not be identified as a normative need by health professionals. A need may be felt and identified as a normative need but is not expressed e.g. the need for psychiatric interventions. A need may be felt, expressed and identified as a normative need e.g. someone experiencing severe chest pain and going to accident and emergency, and a need may not be felt, but it is expressed and identified as a normative need (Bradshaw, Popay and Williams, 1994).

Multidimensional needs: These are needs in the different dimensions of a person's life including physical, psychological, social and spiritual dimensions.

Physical needs: Needs pertaining to the well-being of the body and its organs, it includes the need for symptom control.

Psychological needs: Needs that pertain to one's emotions and thought processes.

Spiritual needs: Needs related to the way one finds meaning and purpose in life.

Social needs: Needs that pertain to one's relationships with one's self, family and the community and one's daily living.

Information needs: Needs related to getting knowledge on health related issues.

Patients/ participants:

From the literature there is no consensus on the terminology that should be used when referring to ill people involved in research. This was a challenge for me when deciding on the appropriate terminology to use in writing up the thesis. After review of the different terms in literature, I chose the term 'patients' to refer to people with HF who participated in this research but during the interviews, in the research field, I referred to people by their names. The term 'patients' was chosen to draw the reader's attention to the fact that these were hospitalized people that were receiving medical care during the time they were recruited for the research. Additionally, because there was more than one group of participants in this research (including their carers and the health professionals) the term 'patients' was used to identify this particular group of participants from the other groups of participants, a practice recommended by Jackson (1999). 'Patients' is also a long established term in most medical publications and may be more acceptable in publications intended for health care professionals for whom this research is intended. (Jackson 1999)

However, the term 'patients' may not be appropriate at all times for these people as explicated by Conrad (1990) that chronically ill people spend only a small fraction of their time in the patient role and being a patient is only one aspect of being ill, therefore the use of the term in research may lead to the study of only 'patienthood' instead of the illness experience. I took caution to avoid studying only 'patienthood' in this research by studying people's holistic experiences. Even with that caution

taken, the use of the term ‘patients’ in this research may have been irrelevant especially during the follow up interviews when some of the people were stable, did not feel sick and were not hospitalized. (Wing 1997) Furthermore, Wing (1997) suggested that the term ‘patients’ may convey unacceptable attitudes and may suggest a paternalistic relationship that infers a lower status to the patient in decision making. However, several studies have shown that most people with illness do not find the term demeaning and prefer to be called ‘patients’ by their doctors (Wing 1997. McGuire-Snieckus 2003) and the term no longer implies passivity. (Jackson 1999) The choice of the term ‘patients’ in this study was also influenced by my medical background and this mindset could have influenced my behavior towards these people and my interpretation of the results of the study.

The term ‘participants’ was also used in this research to show that the people who took part in the study were involved in the research process as active participants and not passive subjects. The term ‘participants’ is now more acceptable in research because it denotes a more collaborative interviewing relationship (Chalmers 1999) and some researchers argue it is a way of expressing respect for those people who accept to be involved in research studies and who are making an active contribution to the process. (Corrigan 2006). I also used the term ‘participants’ to show that these people were not always in the patient role since some people were later interviewed in their homes and they saw themselves as normal at that time. Despite the term ‘participants’ being widely accepted for people involved in medical research some authors are ambivalent on whether the term ‘participants’ is appropriate for all those recruited in research as some of these do not actually participate actively (Corrigan 2006). I felt that people that were involved in this study actively participated in this research by giving their life stories and therefore fit the definition of ‘participants’. However, when a study has more than one group of participants (such as this study) using the term ‘participants’ may lead to loss of clarity as to which group is being referred to (Jackson, 1999) that is why the term ‘patients’ was used sometimes.

The narrative voice: Most of the narrative voice used in this thesis was passive and I chose not to use the pronoun ‘I’ in most of the narrative in the thesis except in the methods section. I used the pronoun ‘I’ in the methods section so as to clarify what I had done as a researcher. My choice of not using the ‘I’ pronoun in most of the

narrative was influenced by what I thought would suit the audience for which this research is meant which is the medical and nursing professions. The tradition in these professions is to avoid use of the 'I' pronoun, this is probably because most research in these professions and the other medical sciences is positioned in the positivist paradigm where objectivity is crucial. Most research reports in the sciences therefore avoid using the 'I' pronoun and often see the first person as interfering with objectivity and impersonality. However, avoiding use of 'I' can lead to vagueness and lack of clarity as to whose ideas are being conveyed. The reader may not be able to tell whether it is the researcher's original idea or an existing idea in literature because statements may sound less emphatic and less direct. By avoiding the use of 'I' my original ideas and how they departed from the work of others may have been blurred into general ideas. Therefore, where I thought there may be lack of clarity I used the pronoun 'I' especially in the methods section.

ACRONYMS

APCA African POS: African Palliative Care Association African Palliative Outcome Scale

CPD: Continous professional development

CVDs: Cardiovascular diseases

HF: Heart failure

NCDs: Non-communicable diseases

NYHA: New York Heart Association

QOL: Quality of life

HP: Health Professionals

HRQOL: Health-related quality of life

SSA: Sub-Saharan Africa

UN: United Nations

WHO: World Health Organization

PC: Palliative care

POS-S: Palliative care outcome scale- symptoms

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CHAPTER ONE

1.0 Introduction

This chapter provides an introduction to the research and the story behind the research questions that establish why the thesis is timely and valuable in the current global health context. Heart failure (HF) is increasingly recognised as a major illness having an impact globally, especially in the African region and in Uganda in the framework of the looming epidemic of non-communicable diseases (NCDs). The chapter describes the research problem in the context of the study setting and introduces the concept of the chronic illness experience, which is a central area of investigation for this research.

1.1 The significance of non-communicable diseases globally and particularly in Sub-Saharan Africa

NCDs (which include cardiovascular diseases, diabetes, cancers and chronic respiratory diseases) are the leading cause of death globally (WHO, 2014). In 2012, 38 million of the 56 million deaths that occurred worldwide were attributed to NCDs and almost three-quarters of deaths due to NCDs (28 million) occurred in low and middle-income countries (WHO, 2014). The burden of these diseases is rising fastest in low-income countries with significant social and economic impact. Africa is facing a dual epidemic of disease, for although the majority of deaths are still due to communicable diseases, it is projected that annual deaths due to communicable diseases will decline but deaths due to NCDs will increase, and they will be the leading cause of death by 2030 (Abdesslam and Boutayeb, 2005. WHO, 2011. WHO, 2014).

Uganda, like many African countries, has not yet achieved the Abuja Declaration target of allocating 15% of its GDP to health (Piot and Seck, 2001. Korte, Rehle and Merkle, 1991. Tangcharoensathien, Evans and Marten, 2013. UNAIDS, 2013), and health services are significantly under-funded. Lack of funding has led to the neglect of NCDs and concentration on communicable diseases within many countries' Essential or Basic Health Plans (Kapiriri, Norheim and Heggenhougen, 2003). However, over the last few years, particularly leading up to the UN High-Level

Summit on NCDs in 2011, there has been growing interest in NCDs and a recognition of their increasing presentation in the region (United Nations, 2011).

1.2 The significance of cardiovascular diseases as a subgroup of non-communicable diseases

Cardiovascular diseases (CVDs) contribute to most of the mortality attributed to NCDs, globally estimated at 46.2 %, followed by cancer 21.7%, respiratory disease 10.7% and diabetes 4%. These four conditions contribute to more than 80% of NCD deaths (WHO, 2014). Cardiovascular diseases are also a significant cause of mortality in many developing countries within Africa, where they account for almost 30 % of deaths (Fuster and Kelly, 2010. Ntusi and Mayosi, 2009. Santulli, 2013). Heart diseases are the leading cause of mortality among CVDs globally, accounting for 66% of CVD deaths in males and 62% of CVD deaths in females (Mendis, Puska and Norrving 2011). Ischaemic heart disease is the leading cause of heart disease globally, accounting for 45% and 37% deaths due to CVDs in males and females respectively (Mendis, Puska and Norrving 2011). A double burden of infectious and non-infectious causes of heart disease has been observed in Africa, with a reported increase in some countries of ischaemic heart disease, most probably as a result of urbanization (Kayima et al., 2011). Patients with heart disease in Africa commonly present with HF which is a complication of these diseases (Okello et al., 2013).

1.3 Heart Failure in Africa and Uganda

Causes

HF has emerged as a common CVD in Africa (Ntusi and Mayosi, 2009) and is a common reason for hospital admissions due to heart disease. It accounts for 3-6% of hospital admissions (Kingue et al., 2005. Oyoo and Ogola,1999). The majority of HF cases in Africa are due to non-ischemic causes. Rheumatic heart disease, hypertensive heart disease and cardiomyopathy account for 75% of cases, cor-pulmonale and pericarditis for 20% cases, and a small proportion of patients are accounted for by ischaemic heart disease (Damasceno et al., 2007. Khatibzadeh et al., 2013. Grimaldi et al., 2014). In 2006, in Mulago Hospital, the National Referral Hospital for Uganda, causes of HF in decreasing order of prevalence were found to include rheumatic heart disease, dilated cardiomyopathy, hypertensive heart disease, endomyocardiofibrosis,

degenerative valvular heart disease, hypertrophic cardiomyopathy and ischaemic heart disease (Kuule, Seremba and Freers, 2009). In an unpublished review of records performed in April 2012 in preparation for this PhD on the recently established database of patients admitted to the cardiology division in Mulago hospital, it was found that 2015 patients had been admitted with heart disease from March 2011 to April 2012. Of these 344 (17%) were admitted with HF, 66% were female, 62% came from the capital of Uganda, Kampala, where the hospital is situated and within 30 kilometers. There were two peak age groups of presentation: those between 20 to 40 years and those between 50 to 80 years. The commonest causes of HF were hypertension 35%, cardiomyopathies 24%, rheumatic heart disease 14%, ischaemic heart disease 4%, and arrhythmias 2%. In 21% of the records, the cause was not documented. Rheumatic heart disease and cardiomyopathies were the predominant causes of HF in the 20-40 age group and hypertension in the 50-80 age groups. There were few cases of ischaemic heart disease. These findings contrast with findings in the developed world where HF is almost entirely in the age group of 60 years and above and is mostly due to ischaemic heart disease.

Presentation of heart failure in Africa and its impact

The majority of patients with HF in Africa, present at an advanced stage. A study in Mulago Hospital revealed that 59.9% of HF patients presented with New York Heart Association (NYHA) functional Class III, 36.9% NYHA functional Class IV and the rest were in NYHA functional class II, with none in NYHA functional class I (Kuule, Seremba and Freers, 2009). In Kenya, a neighboring country, the majority of patients presented in NYHA functional class IV HF (Oyoo and Ogola, 1999). HF, particularly when advanced, has a considerable impact on quality of life because of the associated high symptom burden and subsequent multi-dimension impact. The terminal phase of HF has been found to have similar symptom burden and distress as cancer in studies done in the USA (Bekelman et al., 2009. Zambroski et al., 2005). In Nigeria in Africa, patients with advanced HF were found to have similar scores to patients with major depression on mental health scales for health-related quality of life, and a large proportion of these patients had depression (Ansa et al., 2009, Ola et al., 2006). The majority of patients with HF in Africa are younger than those with HF in high-income countries (Damasceno et al., 2012). Having more young people affected with HF has significant implications for economic development and for the

social circumstances of these patients and their families who care for them because this is the most productive age group. Patient earnings are reduced as are those of their informal carers, and neither group can contribute to the national economy, so government productivity also declines. Many of the health care costs in low-income countries, including Uganda, have to be paid out of pocket. Therefore conditions such as HF with a prolonged course and life-time treatment lead to impoverishment further affecting patients' and their families' quality of life. HF also has a significant impact on the health care system in Africa as repeated hospital admissions characterise the course of the illness. In the THESUS-HF study that investigated the causes, treatment and outcomes of HF among 1,009 people in 9 countries in SSA, Uganda inclusive, the rate of readmission and death by 60 days was 15.4% (Damasceno et al., 2012). Several studies conducted over the last 10 years estimate that 1% of the health budget in Africa is spent on treatments for HF, but the indirect costs of HF in low-income countries are even higher than this (Damasceno et al., 2007. Cook et al., 2014).

Management, care and outcomes for heart failure

In the routine management of HF in Uganda only those symptoms and problems related to functioning (such as those used to determine the NYHA functional class) are assessed, treated and monitored. Other symptoms and other multidimensional needs that are commonly reported in high and middle-income country literature and which cause considerable distress to patients are not well documented in the African literature, nor are they taught within medical under or postgraduate curricula and therefore are unlikely to be identified by busy practitioners. Besides affecting ones' quality of life, symptoms are important predictors of mortality and readmission and, therefore, should be a target for treatment in their own right (Ekman et al., 2005, O'Connor et al., 2012). While the majority of the recommended diagnostic tests, and medications that have "mortality benefit" for HF are available in Uganda, these are often not accessible to most patients because they have to be purchased and patients cannot afford them. The suboptimal use of these drugs is described in the THESUS-HF study (Damasceno et al., 2012). Since 2011, a number of surgical procedures for some causes of HF are being carried out in Uganda but as these procedures are exceptionally costly, they are also beyond the reach of the majority of patients. It is estimated that 37.9% of Ugandans and 46.8% of the total African population live on

less than 1.25 US dollars a day (World Bank, 2015), and yet it is this group of the population that is predisposed to the infectious causes of HF that require expensive surgery. Even for those who can afford treatments at the start of their illness, sustaining prolonged treatments is a challenge due to high costs.

Even without the above challenges, the prognosis of HF is poor even in high-income countries, with life expectancy at five years being 62 % for men and 42 % for women from the onset of disease (McKee et al., 1971). In a UK study in 2011, the researchers showed that the five-year mortality from HF was worse than that for bowel cancer for men and breast cancer for women (Stewart et al., 2001). In Uganda, the mortality rate at two weeks for those admitted with advanced HF has been reported as 10.2% (Kuule, Seremba and Freers, 2009). In the THESUS-HF study, the mortality rate was 10.6% at 2 months and almost 20% at 6 months (Damasceno et al., 2012). The above circumstances and needs indicate the importance of putting in place a palliative care approach informed by patients' experiences to address the multidimensional and end of life care needs of patients living with HF. Uganda has made significant progress in Africa in developing palliative care services (Grant et al., 2011), but these are mainly focused on HIV/AIDS and cancer with almost no home care services for patients with organ failure including HF.

Most HF care management in Uganda is based on evidence from Western literature although recent ongoing research has commenced with the current interest in the NCDs epidemic. There is no peer-reviewed literature that reports the first-hand experience of Ugandan patients with their illness, their multidimensional needs over the illness course, their experience of the process of diagnosis and treatment, what they perceive of their care and what they want to be improved. (Selman, Brighton and Harding, 2015).

1.4 The study context

The study was based in Kampala, Uganda, within the national referral hospital, Mulago Hospital. Interviews were carried out in the hospital and the homesteads of patients. Uganda is situated in East Africa and has a population of 34.9 million people (Uganda Bureau of Statistics, 2014) from over 40 different ethnic origins, with over

40 different languages. The literacy rate is estimated at 73% (Uganda Bureau of Statistics, 2014) and the main languages are English (the official language), Luganda and Swahili. The majority of Ugandans in Kampala speak Luganda, which is the mother tongue of the Baganda people who mostly live in and around Kampala. Secondary school education is conducted in English. The age structure of the population is a pyramidal structure: 56.7% are between 0-18 years, 18.4%, 18- 30 years, 20.7% 31-59 years and 4.2% in the age group of 60 years and over (Uganda Bureau of Statistics, 2014). Life expectancy at birth is 50 years and the gross national income per capita is $600 as compared to $41,680 in the UK (World Bank, 2015).

NCDs are becoming increasingly important as causes of morbidity and mortality in the Ugandan population. Records from the Uganda Heart Institute in Mulago demonstrate a 500% increase in outpatient attendance due to heart-related conditions between the years 2005-2009 (Ministry of Health Uganda, 2014). In Mulago Hospital, causes of heart disease among 1,200 patients admitted in the cardiovascular division in the year 2010 included; hypertensive heart disease 40.1%, rheumatic heart disease 20.1%, cardiomyopathy 15.5% and ischaemic heart disease 10.1% (Kayima et al., 2011). In one unpublished Internal Medicine student's dissertation that looked at the pattern of cardiac disease in Mulago Hospital in Uganda, 86.5% of patients with heart disease presented with severe HF (Achadu 2003).

Factors associated with this epidemiological transition and doubling of the burden of diseases in Uganda through communicable disease to NCDs include: an increasing aging population, urbanisation, mechanisation, sedentary living and prolonged use of drugs used to treat HIV/AIDS (Maher, Smeeth and Sekajugo, 2010). An NCD programme in Uganda was established during the 2006/2007 financial year plan to help implement actions aimed at controlling and preventing these conditions (Schwartz et al., 2014). The health system faces many resource challenges with only 8.2% of its Gross National Income allocated to health (WHO 2012). Additionally Uganda has severe workforce crises with a doctor-patient ratio of 1: 24,725 (WHO recommended 1:10,000 in Africa) and a nurse-patient ratio of 1:11,000 (WHO recommended 1:400) and 0.5 hospital beds per 1,000 population (Budget Monitoring and Accountability Unit, 2013).

Mulago National Referral Hospital

Mulago Hospital is the national referral and teaching hospital in Uganda located in the capital of Uganda, Kampala. It serves the population around Kampala as a primary health care centre and also acts as a specialist referral centre for all the districts in Uganda as well as receiving patients from the east of Congo, the south of Southern Sudan, the west of Kenya and the north of Rwanda. It is exceptionally busy with a bed capacity of 1,600, but it may have as many as 2,000 patients at any one time. In this hospital, patients with HF can be admitted to two different wards: a) the cardiology unit in the Department of Medicine which is a general ward and b) the Uganda Heart Institute which is a private semi-autonomous unit within the hospital. Patients are admitted to the Uganda Heart Institute to their preference and if they can meet the costs of admission to a private ward. The general ward does not charge admission costs. HF services offered in Mulago Hospital include diagnostic and treatment services. The majority of basic diagnostic services and treatments in the general ward are free of charge, but patients often incur costs for the more expensive medications. These are usually the newer drugs believed to be more efficacious. Patients may also incur costs on some diagnostic tests if they are not available within the hospital, but available at some of the local, private laboratories. It is not uncommon to have drug stock-outs because the hospital runs above capacity and exceeds its health service budget and therefore patients frequently are forced to buy medications outside the hospital in local pharmacies. For many patients who have little or no income, such costs are prohibitive. In a study conducted at Mulago Hospital in 2011, the median daily income of patients in 2009 was £1.20 and the range was £0-£226 (Lewington et al., 2012).

Patients may be admitted to the hospital wards from the hospital heart disease outpatients' clinic or may come to the hospital wards from the Emergency Ward. The hospital heart diseases outpatients' review clinic is run twice a week and patients with heart disease, including those with HF, who have been discharged from the hospital and new patients with these conditions who do not need hospitalisation are reviewed in this clinic. Although there is a structure and a system of patient referral across the different levels of the Ugandan National Health Care System which should ensure that all patients are seen in health centres in their local areas, this rarely happens (Ministry of Health Uganda, Health Systems 20/20 and Makerere University

School of Public Health, 2012). There is no clear documented reason for this systems dysfunction, but assumptions are that many of these lower level referral centers do not have enough health professionals and resources such as drugs and so patients continue to come back for review and specialist care in Mulago Hospital. An increased effort is being made to establish and enhance this primary care system but to date there are no home care services for patients who do not have cancer or HIV/AIDS. Follow-up is not routine, and some patients choose to attend for routine review as scheduled by their physicians; others attend only when their illness increases and they begin to feel less well. In the last two years an electronic database has been established at Mulago Hospital. However it remains difficult to know which patients are attending the outpatient clinic, and which patients have been readmitted to the hospital.

Mulago Hospital has a hospital palliative care unit that was established in 2006. It is a free consultancy service that cares for patients from across the hospital and works collaboratively with home-based care services to which patients are referred at discharge. These home care services predominantly care for patients with cancer and HIV/AIDS with almost no options for the provision of home-based palliative care for other patients except on special request. It is uncommon for HF patients in the hospital to be referred to the hospital team for palliative care, and understanding why this was so was part of this study. A study carried out in Mulago Hospital to determine the need for palliative care found that out of the 1,763 patients in the hospital 37.7% had palliative care needs. HF patients constituted 9.2% of the 37.7% but only one patient with HF had been referred for palliative care (Jacinto et al., 2014). A Palliative care link nurse programme was developed in 2011 by the palliative care team. Selected nurses working on different wards in the hospital have been given basic training in palliative care and provide a liaison role identifying patients who may need a palliative care approach. They are also skilled to offer generalist palliative care and refer on to the specialist team if the patients need specialist care.

1.5 Rationale for the study

Comprehensive, multidisciplinary management of HF must include palliative care. Palliative care is important for improving treatment outcomes such as the quality of

life, survival, reduction in hospital admissions and increasing deaths at home (Desrosiers et al., 2014). Palliative care aims at improving QoL through addressing multidimensional needs and indeed improved survival, and improved QoL has been demonstrated in HF patients receiving palliative care compared to those without it (Connor et al., 2007. Evangelista et al., 2012). QoL is also associated with survival in HF (Hoekstra et al., 2013). QoL is a subjective phenomenon that can be better understood through the patients' perspectives by understanding their experiences. Therefore, for palliative care to be effective, patients' perspectives on their needs, what is important to them and their experiences have to be taken into account. With the looming NCD epidemic, palliative care services need to plan for the care of patients with advanced non-cancer or non-HIV/AIDS conditions including HF. Existing services that are cancer and HIV centred may not necessarily meet the unique needs of patients with these diseases. Several studies have been done in high-income countries to understand the experiences and identify the needs of patients with HF, but there is very limited information on the holistic/ palliative care needs of HF patients in SSA (Selman et al., 2015), where the demographics and causes of HF are different and also the social, spiritual and cultural factors and circumstances are different. This study aims to add value to the currently limited literature, and to begin to establish an evidence base on patient documented need in this context. The information generated on the needs of patients within their disease trajectory and on what constitutes well-being and quality care is aimed at enabling generalists, cardiologists and palliative care clinicians to plan interventions that are tailored to needs.

The right to health and the right to engage in the planning and implementation of their health care is enshrined in the Alma-Ata Declaration of 1978 (Fendall, 1978). This study aims to highlight people's views concerning their care especially as incorporating patients' experiences and their opinions in planning of care has improved services in others settings (Wagner et al., 2001). Using information from patients in service planning is important for the uptake of services and patient satisfaction (Mandelblatt et al., 2006). Given the current new investment in establishing an evidence base for the control and management of NCDs in Uganda and across SSA this study comes at an opportune time. This study will provide information to policy makers on what is perceived as working well alongside the

deficits that exist in service provision from the perspectives of the healthcare providers and the patients, to help target interventions.

1.6 The experience of living and dying with a chronic disease

1.6.1 Understanding the chronic illness experience

HF is a chronic illness and in advanced stages it is life-limiting (Stewart et al., 2001). An understanding of the experience of living and dying with a chronic illness was sought to help better understand the HF experience. Chronic illness has attracted much research interest in social medicine due to its prominent psychosocial impact that tends to be similar for the different chronic illnesses (Nettleton, 1995. Kelly P, 2010). Interest in the sociology of chronic illness has driven theory development that has contributed to an in-depth understanding of the nature and the repercussions of these conditions. One of the significant developments in this area has been the recognition of the different explanatory models used by health professionals and patients to explain ill-health (Helman, 1981). These explanatory models have led to redefining and reconceptualisation of disease and illness. Kleinmann, Eisenberg and Good define disease as "*the abnormalities in structure and function of the body organs and systems and illness as experiences of disvalued changes in states of being and in social function; the human experience of sickness"* (2006, p141). Recognising the difference between disease and illness is central in matching medical care to patients' needs and expectations, (Kleinman, Eisenberg and Good, 2006) and has been pivotal in identifying models of care that are suitable for acute and chronic illnesses.

Traditionally in clinical teaching in African medical schools, the medical model has been used to understand and explain all ill-health. This model is the foundation of evidence-based practice in health care and has been very successful in acute diseases and in acute episodes of chronic illnesses (Abelson, Rupel and Pincus, 2008. Kramer-Kile and Osuji, 2012). The biomedical model has, however, been criticised for its disease-oriented focus, and its failure to engage with those living with illness and their families making it limited in addressing chronic illnesses (Nettleton, 1995. Abelson, Rupel and Pincus, 2008). Engel proposed an alternative model, the bio-psychosocial model (Engel, 1981) which has gained wide acceptance in health

training in high-income countries (Wade and Halligan, 2004), including in palliative care. Fava and Sonino drawing on the work of Engel explain that "*the bio-psychosocial model allows illness to be viewed as a result of interacting mechanisms at the cellular, tissue, organism, interpersonal and environmental levels*" (2008, p2). They argue that "*the study of every disease should include the individual, their body and their surrounding environment*." (Fava and Sonino, 2008, p2). The proponents of the use of the bio-psychosocial model do not refute the importance of the biomedical model, but argue that it could be expanded to include social and psychological aspects for better patient experience (White, 2005). However, the bio-psychosocial model on its own is not exhaustive as it is deficient of important concepts such as spirituality that have been found to be important in the chronic illness experience but it provides a broad structure upon which other models can be built and expanded.

1.6.2 The concept of the patient's illness experience

Important for this research study is an understanding of the concept of the illness experience that will facilitate in-depth inquiry into this subject. Conrad (1990) observed that most research on illness experience gives narrative accounts of living with the illness. He suggests that the concept of the illness experience should be developed and broadened to include clients' experiences before they become patients, their experience and perceptions of medical care, experience beyond the medical settings, the meaning of illness, the social organisation of the sufferer's world and the strategies used in adaptation. He also proposes that the focus should be on patients' everyday lives, living with and despite the illness, and it should be from a sufficient number and variety of people. He argues that illness is more of a social phenomenon than a physiological phenomenon as it has to do with perception, behaviour and experience (Conrad, 1990). His suggestions convincingly give a broader concept of the illness experience and resonate with experiences in Uganda. However, there is a significant physiological contribution to illness that should also be examined as the trigger to perception and behaviour is the physiological abnormality or the symptoms, thus all these aspects are important to understanding the illness experience. Kelly and Field, therefore, provide a theoretical link between biological and social facts in the illness experience by acknowledging that the physical facts have both a physical and social reality (Kelly and Field, 1996). Kelly (2010) drawing on the work of different sociologists develops this notion further when he highlights that "*symptoms are more*

than biochemical changes in the body but they affect the sufferers daily lives" (2010, p1). He, therefore, illustrates the importance of the symptom experience in the illness experience. Sufferers of chronic illness develop their perceptions of the illness, including the symptom experience, and these perceptions influence their behaviour with the illness, leading to the illness experience. These sub-concepts of the illness experience are discussed below.

The symptom experience

The initial literature that described symptoms and the concept of the symptom experience focused on the multidimensional nature of symptoms (nature, intensity, duration and frequency), the distress symptoms caused and the factors that influenced the perception of symptoms. Most of this initial research also employed the quantitative paradigm (Lenz et al., 1997. Rhodes et al., 2000). However, as Armstrong (2003) observed, this concept was limited in describing the full symptom experience. Building on the above concept, Armstrong developed a broader concept of the symptom experience to include; symptom occurrence (nature, intensity, duration and quality) the distress caused by the symptom, the meaning of the symptom, the antecedents and the consequences of the symptom (Armstrong, 2003). Armstrong's concept of the symptom experience fits well with qualitative research and was adapted in understanding the symptom experience in this study. Armstrong's (2003) argument for inclusion of the meaning of symptoms and their consequences in the symptom experience is backed up by Kelly's statement that research on the illness experience has revealed that "*symptoms have an impact on the person particularly on the way people think about the symptoms, manage them and relate to others in spite of and because of the symptoms*" (2010, p1). What people think of their symptoms and how they interpret them is perhaps what is often referred to in the literature as '*illness perceptions*' and how they manage the symptoms and relate to others in spite of and because of the symptoms as '*illness behaviour*.' Therefore the symptom experience, patients' perceptions of their illness and their illness behaviour are intimately linked and influence the illness experience.

Illness perceptions

Larsen and Lubkin (2009) reviewed the literature on illness perceptions and describe illness perceptions as the ways in which the patients and the family view their illness.

Illness perceptions may not conform to scientific beliefs, but are shaped by one's social interactions, understanding of the diagnosis, the information they get from lay and professional people, past experiences, their semantic knowledge, age, personality and culture and they change over the illness course (Larsen and Lubkin, 2009. Petrie and Weinman, 1997). Different cultures may have different narratives of chronic illness which will shape the way a person in that community perceives their illness (Lawton et al., 2007). From the literature, it appears that the central determinant of one's illness perceptions is the amount and type of information they have about the illness and how they process and interpret that information. Illness perceptions affect the emotional response to the illness, coping and behaviour leading to the observed illness behaviour.

Illness behaviour

Illness behaviour is the way patients behave given the presence of symptoms (Nettleton, 1995). Parsons (1951) was among the pioneers in describing illness behaviour. He introduced the concept of the sick role in which he explained that when patients are considered and defined by the community as ill, they are then allowed to take on the sick role and within this role,they are accorded the right of being exempted from duties in their community and in return these sick people are expected to get better as soon as possible by their community (Parsons, 1951). The sick role model of illness has been critiqued and deemed irrelevant in chronic illness because it presumes a temporary illness period whereas chronic illness is a permanent state where one cannot permanently be exempted from their duties and therefore some authors argue that in chronic illness, the emphasis of the illness behaviour is on improving function in spite of the illness (Larsen and Lubkin, 2009). Vallis and McHugh (1985) suggested a model of illness behaviour in chronic conditions that looks at the subject on a continuum and assimilates the biological, psychological and social-cultural aspects of the individual's experience. Their model of illness behaviour includes the following concepts: disease-illness distinction through cognitive appraisal and affective integration; the impact of socio-cultural variables; and coping (Vallis and McHugh, 1985).

Illness behaviour is influenced by social, cultural and psychological factors including ones' norms, values, fears, expected rewards and punishments, these impact on how

an individual with illness acts (Mechanic and Volkart, 1961). *Other factors that influence illness behaviour include: demographic factors such as marital status, gender and age; past experience including one's education, learning, and socialisation; social and cultural background; and the culture of poverty which influences development of traits such as dependence, fatalism, inability to delay gratification, and a lower value on health. Some behaviours are learnt in childhood through parents' modelling and reinforcing of symptoms in their children* (Larsen and Lubkin, 2009). Illness behaviour includes seeking care, adherence to treatment and self-care. Illness behaviour, therefore, has a significant influence on the illness experience because the choice of whether one seeks care, adheres to treatment or cares for self will influence their illness outcome and experience.

1.6.3 The chronic illness experience - existing theories

Over time there has been a paradigm shift in understanding chronic illness from the 'outsider perspective' typified in the Parsonian concept of the 'Sick Role' to an 'insider perspective' concerned with patients' subjective experience outside and within the medical context (Lawton, 2003). Several authors have contributed to substantial theory development in this area.

Biographical Disruption

Bury (1982) introduced the concept of 'biographical disruption' and described chronic illness as a major disruptive experience where '*structures of everyday life and forms of knowledge that support them are disrupted*' (1982, p69-70). He described three aspects of disruption. Firstly *'disruption of taken for granted assumptions and behaviours as chronic illness exposes the sufferer to the worlds of pain and suffering possibly even death, that are usually seen as a predicament of others. Secondly there is a significant disruption in explanatory systems normally used by people leading to fundamental re-thinking of the person's biography, their self-concept and expectations and plans the individual holds for the future. Lastly, the sufferer responds to disruption by mobilising resources in facing an altered situation*. (Bury 1982, p70) He explains that this situation brings individuals, their families, and wider social networks face to face with the character of their relationship as normal rules of reciprocity and mutual support are disrupted, especially with growing dependency (Bury, 1982). In a later article Bury (1991) elucidates that biographical disruption is

often followed by a stage of explanation and legitimation, when people begin to face the longer-term implications of their modified situation and gather information to answer the questions 'why me?' and 'why now?' If medical information is not sufficient they may develop pessimist responses and they may supplement this information with 'narrative reconstructions' as described by Williams (1984) (see next section). The narratives help to place such information in a more meaningful context. Bury also explicates that during this process individuals are trying to make sense of their illness and re-establish integrity when the self is shattered, which he views as an attempt to repair disruption. In this process patients search for treatments that make sense using the information they have. New treatments may lead to hope, frustration (based on their usefulness) and side effects, and patients engage in experimentation on different treatments to find out what works. Effective treatment facilitates movement to the next stage that is adaptation to a disrupted biography or achievement of a degree of stability (Bury, 1991). Bury also helps to illuminate ways in which people with chronic illness may adapt to it. One way is by coping and this involves a cognitive process where one tries to maintain a sense of value and meaning in life in spite of symptoms. Another way of adaptation is 'mobilising resources to maximise favourable outcomes, which he terms as a person's strategy'. (Bury 1991) Strategies for adaptation include actions to maintain hope and a sense of the future including attending church and self-help groups where there may be practical advice and 'personal talk'. People adapt using different styles presenting important features of their illnesses or treatment regimens and this is influenced by a person's culture as well as their sense of self, and their knowledge base (Bury, 1991).

Other authors have critiqued the concept of biographical disruption arguing that it is too limited because it presupposes illness entering a life previously not familiar with crisis or struggle and it considers one's age and not their whole biography (Lawton, 2003). The concept is also criticised for not taking into consideration that people are continually appraising their biographies (Williams, 2000). This concept, therefore, doesn't apply well to situations where chronic illness may be expected such as within the elderly where many see illnesses such as arthritis, as a normal part of ageing. Nor does it translate well to those living with HIV who anticipate other chronic illness (Eborall et al., 2007). The critique led to the introduction of further concepts including 'biographical anticipation', 'biographical uncertainty' and 'biographical re-

enforcement' (Carricaburu and Pierret, 1995. Lawton, 2003. Williams, 2000). Even with all these criticisms Bury's theory is central to understanding the illness experience and may be very suitable for populations that are young such as in Africa, however the other concepts have been useful in expanding the theory of biographic disruption to other situations. Bury's contention that with the onset of chronic illness there is a biographical disruption whereby in addition to physical problems, the illness assaults a person's sense of identity and self-worth leading to loss of confidence in social interaction, points to the need to analyse and understand the way patients see their identity and their needs. Understanding how the meaning of illness changes in a given context and throughout the course of the illness is important. By using Bury's typology of two types of meaning an illness holds: the first being the consequences or impact of the illness on the individual and the second being the different 'connotations and imagery' the illness is accorded in a given context (Bury, 1991), provides a shape to the work of eliciting the patient experience.

Narrative Reconstruction

Williams (1984) introduced the concept of narrative reconstruction in which he showed how peoples' accounts of the origin of their illness are not just concerned with beliefs about the disease aetiology but also include events they consider significant in their past. He explains that often people will add a moral and sometimes political component to their stories so as to find a meaningful place of the illness in their lives (Williams, 1984. Lawton, 2003). This shows that when given information about illness people do not just take it as it is, but process it to come up with a narrative that is meaningful to them. Williams' theory provides a framework upon which patients' stories can be analysed. His theory on narrative reconstruction neatly links into Bury's theory of biographical disruption because it illustrates people's responses to disruption by explaining how people try to make sense of their illness. Bury further develops Williams work by explaining that these narratives are an attempt to reconstruct a sense of order from the fragmentation produced by their chronic illness and to place information into a more meaningful context (Bury, 1991). Bury identified three types of narratives namely: *'contingent narratives which represent the beliefs and knowledge about factors that influence the onset of the illness, its emerging symptoms and its effects on the body self and others or the practical and emotional consequences of managing symptoms in everyday life; the*

'moral narrative' which introduces an evaluative dimension into the links between the personal and the 'social'; and the 'core narrative' which constitutes the form or structure of the narratives that is whether heroic, tragic ,comic romantic (Bury, 1991). These narratives provide a template for understanding how people make sense of their illness.

The loss of self-construct within chronic illness

Charmaz (1983) described the concept of loss of self (self-conception) as the fundamental nature of suffering in those with chronic illness, in this way she highlighted that suffering in chronic illness is not only physical but multidimensional (Lawton, 2003). She also illustrated how all losses in chronic illness are inextricably linked and exacerbate each other resulting into loss of self. For example, she explicated that loss of self results from ongoing collective losses in peoples' lives including loss of productive function, financial crises, family strain, independence and stigma. Loss of control over people's lives and their futures and loss of those experiences and meanings upon which they built positive self-images leads to loss of self-esteem, self- identity and a diminished self (Charmaz 1983). The multidimensional impact of chronic illness is also illustrated by the resulting restrictions that illness imposes on people's lives, which in turn lead to social isolation resulting in further loss of self. Charmaz (1983) views social isolation as being both physical isolation resulting from the inability to participate in activities, and emotional isolation resulting from inattentiveness and being devalued by significant others. Charmaz also highlighted that one of the other assaults on one's self-image is that of becoming a burden due to physical dependence, failing to meet obligations implicit in past relationships and losing a job (Charmaz, 1983). However, not all people with chronic illness will experience loss of self, some are able to cope with loss and Charmaz (1983) explains that this happens because self-conception evolves over the illness course and replacing a lost self with a new valued self is essential to illness management and coping.

Independence and expression of one's attributes are regarded as central in people's construct of their self- concept in Western culture (Matsumoto, 1999), therefore, Charmaz's findings of the loss of self, resulting from the loss of independence and loss of control, could reflect the Western culture. Also in Western culture self-image is often but not invariably related to body image and therefore illness that impacts on

the physical body affects self-image (Nettleton, 1995). Kelly and Field's (1996) conceptualisation on the relationship between the body, self-image and identity hugely supports Charmaz's findings above. Kelly and Field contend that the body is important in the illness experience because of the central role it has in social life. They explain that the recognition of social development and the measure of the social competence of human beings is centred on the way in which one can control one's physical body. It is because of this that the body is central to the construction of one's self-concept and identity. They describe how one's sense of self, one's self - concept usually parallels bodily experiences, feelings and actions and how one's identity is determined by how others perceive and define the bodily changes resulting from an illness and whether the illness prevents them performing their roles. They further argue that the relationship between self and identity in chronic illness is a social process that alters through time as bodily contingencies change. Kelly and Field (1996) also describe how the body is vital to the coping task because dealing with the physical manifestations of the illness is pivotal and precedes coping in all other areas.

The concept of 'unbounded bodies'

Lawton (2001) ably illustrates the above linkage between the body and self -image and the resulting impact on the illness experience through her concept of 'unbounded bodies' and 'dirty dying'. She illustrated that people who had bodies that were deteriorating and leaking body fluids experienced loss of self, social identity and a loss of dignity. She argued that the state of the body influences patients' choice of place of care as those people in her study that had 'unbounded bodies' chose to be cared for in hospices to avoid being a bother to their families, yet for many this was not initially their preferred place of care before the leakages started. She also noted that there was more withdrawal among 'unbounded' patients even when admitted in hospices, and this culminated in a split of self and body. A common finding amongst these patients was therefore 'mental shut down', where the self left the body behind before actual death, and this happened if their problem could not be fixed. Her study elucidates how conditions such as cancer which affect the 'boundedness' of one's body may affect choice of where one is cared for and may explain why cancer patients are more often admitted to hospices than patients with other degenerative conditions (Lawton, 2001). The findings of the relationship between 'unbounded bodies' and patients' perceptions of loss of control of themselves and their lives are

confirmed by other authors (Probst, Arber and Faithful, 2013). Having the background of the impact of illness on self-concept and the relationship of the body to self-conception provides an important layer to interpret how illness and associated loss is perceived in this study, which was conducted in a context where the culture is less individualistic and where the distinctions between self and community could be blurred.

The role of the 'macro' and 'micro' context in influencing the illness experience

Central to understanding the illness experience is an understanding of the context within which the illness occurs. Lawton (2003) draws attention to how the macro-context such as gendered expectations, stereotypes and the prevailing historical and socio-political context and socio-economic order may influence patients' lived experiences of their illness. The illness experience is also shaped by the micro-context including familial and interpersonal relationships (Lawton, 2003). Pierret (2003) illustrates how the micro level of subjectivity and the macro level of social structure in the illness are interlinked as one's experience is also influenced by health policies, the system of care, the state of medical knowledge, patients' associations and the media. She therefore stresses the need to understand the linkage between meaning of an illness and the consequences of this on the illness experience taking factors such as timing, context, norms and expectations into account (Pierret, 2003)**.** She gives an example of how young patients engage in finding meaning for their disrupted lives to try to establish continuity as they learn to cope with the illness through redefining self, reconstructing and renegotiating identities. These authors clearly articulate the importance of the context in providing a framework within which research findings can be evaluated and that the context considered should go beyond the micro to include the macro to facilitate a broader understanding of the illness experience.

1.6.4 The experiences of dying of chronic illness

Following Glaser and Strauss' (1964) groundbreaking work on dying, several theories and narratives on the experience of death and dying have been advanced in the developed world. Glaser and Strauss's seminal work on dying introduced theories on dying. Their theories on the 'context of awareness and social interaction', 'dying trajectories' and 'dying as a non-scheduled status passage' will be discussed.

The context of awareness and social interaction theory demonstrates the relationship between awareness and interactions and how awareness is central to interaction between the health professional and the patient. Glaser and Strauss' work on dying patients led to the identification of four types of awareness contexts.
The 'open awareness context' where both patient and health staff are aware the patient is dying, the 'closed awareness context' where the health staff are aware but the patient is not aware, the 'suspicion awareness context' where either the patient or health staff or both suspect that the patient is aware that they are dying and the 'pretense awareness context' where both are fully aware but pretend not to be aware (Glaser and Strauss, 1964). They found that most people and their families did not know that they were dying but their health staff knew and therefore there existed a 'closed awareness context'. They illustrated that the closed awareness context led to health staff behaviour that was steered towards concealing information from the patient, increased suspicion and distrust from the patients and missed opportunities for health staff, families and patients in being involved in satisfying rituals in passage to death, hence negatively impacting the dying experience (Glaser and Strauss, 1964).

Glaser and Strauss also conceptualised dying as a temporal process and introduced the concept of dying trajectories. They identified four dying trajectories in their research on health professionals' experiences with the dying : 'swift death'; 'expected lingering while dying'; 'the suspended sentence trajectory'; and 'entry re-entry' (Strauss and Glaser, 1970. Glaser and Strauss, 1974). They further explain that expectations of death and certainty of when it will happen will determine how the patient will be cared for by recognising specific points they termed as 'critical junctures' along the dying, trajectory which are points of transition in the dying process. This will therefore ultimately affect one's dying experience.

Glaser and Strauss (1965) also conceptualised dying as a 'status passage' and demonstrated that if hospital staff know the patient is dying, the patients' experience of dying will be influenced by whether that patient knows that they are dying and if he/she has accepted this status or not. If hospital staff were aware but the patient was not aware this gave control to the former but often raised problems of compliance with treatments but if both knew and the latter accepted their status it would enhance care (Glaser and Strauss, 1965). Glaser and Strauss' theories give useful insights into

the understanding and analysis of what influences the dying process. The important factors highlighted in their work included: the influence of the health professionals' patient relationship; communication between health professionals and patients on the dying experience; and the importance of the use of trajectories in meeting needs during dying. These are enduring concepts to date that illuminate an understanding of the illness experience.

Patients' reactions to death and dying

Kubler Ross (1971) advanced the understanding of dying from the patients' perspectives by describing stages of reactions people go through upon getting to know they are likely to die. These include shock, denial, anger, bargaining, depression and acceptance (Kubler Ross, 1971). She, however, cautioned that not all dying patients go through these stages in this exact order and that some may skip the stages or go back to previous stages. She observed that hope was constant at all of these stages. Her theory was widely adopted because it pioneered work that enabled an understanding of people during dying. However, it has been criticised for being untestable because of the cautions it has, also her labelling of the reactions as stages implicitly infers a set order that is not the course of events in dying (Gold, 2011). Corr (1991) criticised this model for being limited because it focuses on psychosocial dynamics to the exclusion of the physical and to an extent the spiritual, yet dying is complex. To address this limitation, Corr proposed a task-based approach in understanding coping with dying that was multidimensional. He described four major dimensions of coping with dying: that is physical, psychological, social and spiritual dimensions. He argued that these are the main areas of task work in coping with dying which should be used to care for the dying in order to improve understanding, empowerment, participation and guidance for helpers (Corr, 1991). Copp (1997) also contributed to the understanding of dying and how health staff and patients respond to it by introducing the "readiness to die" theory. In this theory, she observed that dying patients and their nurses, while explaining the process of dying, referred to the body and the self as separate. In doing so, nurses came up with conceptual maps on which they could locate each patient. These maps identified four situations that described patients' readiness to die: person ready body not ready; person ready, body ready; person not ready, body ready; and person not ready and body not ready (Copp, 1997).

Their findings showed that these conceptual maps facilitated patient centred care and encouraged open communication between patients and their nurses (Gold, 2011).

1.6.5 Management frameworks for chronic illness

Acute and chronic illnesses necessarily have different management approaches. Kleinman, Eisenberg and Good's work (2006) drew attention to the importance of managing the illness (the total impact of the disease), not the disease (which just focuses on the abnormal physiology), in chronic illness as a way by which patients needs can be fully met. Building on Glaser and Strauss' pioneering work on trajectories of dying, Corbin and Strauss (1991) expanded, defined and described the chronic disease trajectory, and also designed a framework upon which chronic illness could be managed based on this trajectory. They defined a trajectory as the course of illness over time, plus the actions of clients, families and healthcare professionals to manage that course (Corbin, 1998). Their model of the chronic illness trajectory proposed nine phases that represent the different stages of the illness experience. These phases include: the pre-trajectory phase in which risk factors may be identified; the trajectory phase where signs and symptoms are present and a diagnosis workup has begun; the stable phase when illness is under control; the unstable phase of symptoms; the acute phase with severe unrelieved symptoms and or complications of the disease; the crisis phase with critical and life threatening situations that require emergency treatments; the comeback phase with gradual return to an acceptable way of life within the symptoms the disease imposes; the downward phase typified by progressive deterioration and increase in disability or symptoms; and finally the dying phase where there is gradual or rapid shutdown of body processes. Corbin (1998) explains that although this trajectory is pictured as a continuum, patients may move through the phases in a linear or cyclical way, revert to a former phase or plateau for a while. Corbin and Strauss (1991) also proposed a chronic illness framework to match the illness trajectory. This framework has six steps that include: identifying the trajectory phase; identifying problems and establishing goals; establishing plans to meet goals; identifying factors that facilitate or hinder attainment of goals; implementing interventions; and evaluating the effectiveness of interventions (Corbin, 1998). The trajectory model and trajectory framework have provided an important structure for planning of care and timing of interventions in chronic illnesses in high-income countries. Understanding how and if this model and framework could be

translated in a low-income country context where there are health system challenges was one of the aims of this study.

The various theories of living with chronic illness outlined are all contextualised to patients within high-income settings, where health services are resourced and available in a way that they are not in low-income countries. The focus on the individuality of the self, the place of self over community and the role of body image and its relationship to the self are important factors in the theory development. Given the very different communal/ individual relationships in Uganda and indeed in many parts of SSA it is important to explore how these theories provide a lens to understand chronic illness and patient experience and where the theories no longer have resonance because of their roots in a western culture of individualism.

Summary

HF is a common CVD and NCD and a common cause of hospitalisation with significant multi-dimensional impact to the patients, their families and economic impact to the health system in SSA. The majority of patients with HF in Uganda are younger than those in high-income countries and some of the causes of HF in this setting are different from those in high-income countries. The majority of these patients in Uganda present late for care. Late presentation coupled with inconsistent supplies of drugs that improve mortality and a biomedical care approach that mainly targets the disease and ignores symptoms and other multi-dimensional impact, leads to poor QoL and shorter survival. The above circumstances indicate the need for integration of palliative care in HF care in Uganda where palliative care is currently mainly for HIV/AIDS and cancer patients. For palliative care to be effective it is important to understand patients' needs from their perspective hence the need for this qualitative study on the patients' experience of living and dying with HF in Uganda and their needs in the disease course.

Several theories have conceptualised the chronic illness experience in high-income countries. Important theories and concepts from these studies include but are not limited to; explanatory models for disease and illness; biographical disruption; loss of self; role of the body in chronic illness; unbounded bodies; awareness contexts; dying trajectories; dying as status passages; stages of grief; and tasks in coping. These theories have been described above to provide a background for interpreting these study's findings.

CHAPTER TWO

2.0 Introduction

This chapter summarises a review of the literature on the experience of living and dying of HF to give a background to the understanding of the subject. The review aimed to identify and evaluate the empirical and theoretical literature on the experiences of patients with HF, including the physical, psychosocial and spiritual issues that patients face, what their needs are and the extent to which these needs are being addressed by the patients, their families and the health care system. A narrative review was carried out and electronic searches of MEDLINE, EMBASE, CINAHL Plus, PsycINFO, Social care on line, Global health and Global health library were conducted, using the following search terms as summarised in figure 1 and table 1.

Figure 1: Literature search strategy

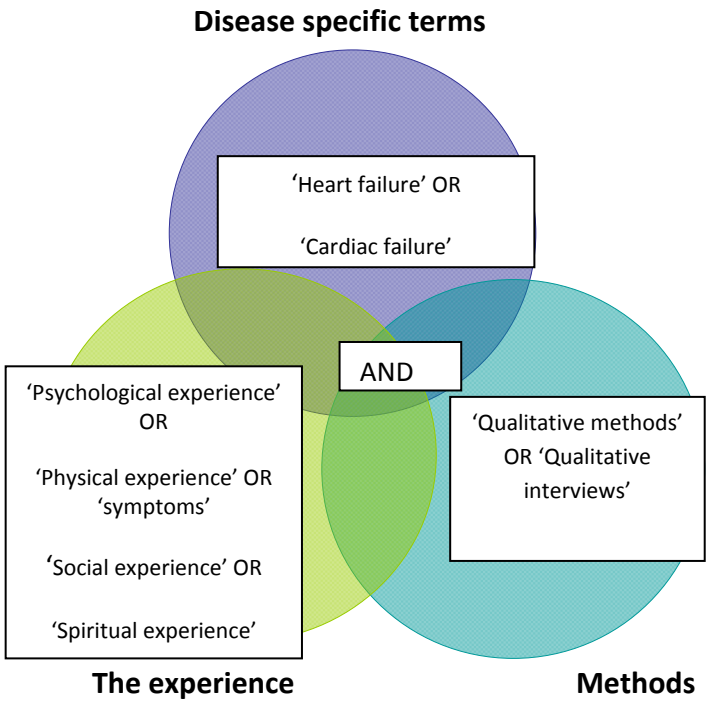


Table 1: Literature Search Strategy

	OR	**OR**	**OR**
AND	**Disease specific terms** 'Heart failure' 'Cardiac failure'	**The experience** 'Psychological experience' 'psychological needs' 'Physical experience' 'physical needs' 'symptoms' 'Social experience' 'social needs' 'Spiritual experience' 'spiritual needs'	**Methods** 'Qualitative methods' 'Qualitative interviews'

The search was supplemented by searches of leading journals in palliative care and by using a snowball approach using references and citations from the identified papers. A total of 14,071 hits were obtained on using the search terms 'heart failure' *OR* 'cardiac failure' *AND* 'Psychological experience' *OR* 'psychological needs' *OR* 'Physical experience' *OR* 'physical needs' *OR* 'symptoms' *OR* 'social experience' *OR* 'social needs' *OR* 'Spiritual experience' *OR* 'spiritual needs'. In order to get more focused articles, the methods were added to the search strategy using subheadings of 'qualitative methods' *OR* 'qualitative interviews' and using the Boolean character *AND* with the previously obtained hits. This brought down the number of articles to 1,135. After excluding duplicates, articles that were not written in English and articles written before the year 2000, 93 papers were deemed relevant and included in the narrative review (For details see appendix 8). The year 2000 was chosen as the earliest date for inclusion of articles to allow for getting as many papers as possible on the subject so as to facilitate an in-depth review of the literature on the subject. Articles not written in English were excluded for practical reasons, as the researcher could not read them. The findings showed that there was strong published literature on the experience of HF patients in the developed countries but there was limited published information from the developing world and especially from Africa, where

only nine papers were identified. The literature from Africa was purely quantitative. The literature also revealed that most studies were done on populations aged 60 years and above. Although there is a significant number of people with HF in Uganda and Africa 60 years and older, there are also a considerable number of patients much younger than this in the Ugandan setting. In addition, the causes of HF are different in the geographical areas. This highlighted the importance of generating information on this subject in this geographical area that has different medical settings, resources, social and cultural circumstances from those in developed countries which may mean that there may be different experiences of the same condition.

2.1 Review of the literature exploring the experience of living and dying of advanced heart failure and the associated multidimensional needs

The studies that looked at the HF illness experience were both quantitative and qualitative and these are included in the relevant sections of the literature review. The literature on this topic can be summarised into the following main categories; the trajectory of HF, the multi-dimensional experiences and needs of HF patients, how patients responded to these needs, the experience with the health care system and health professionals views of patients' needs and how to improve care.

2.1.1 Disease trajectory of heart failure

A landmark study on the trajectory of patients with organ failure that has a bearing on those living with HF was carried out by Lunney et al. (2003) who analysed data of 4,190 decedents with organ failure 60 years and older from the established populations for epidemiology studies for the Elderly (EPESE). They found that their dying trajectories closely agreed with the theoretical trajectories (often referred to as patterns of functional decline) proposed by Glaser and Strauss in 1970 (discussed in section 1.6.7 above). The strength of the study was that it was a large prospective study, which was probably representative of the population, however the data for this study was collected and analysed retrospectively (Lunney et al., 2003). It was also not clear how many of the organ failure patients had HF and whether this trajectory is the same for all organ failure or if there was one type of organ failure that was more common than others that could have influenced the results.

Similar findings to those of Lunney et al. (2003) were observed in a qualitative longitudinal study involving 20 patients with NYHA class IV HF in the community. A pattern of progressive decline punctuated by episodes of acute deterioration and hospitalisation was observed as the common trajectory (Boyd et al., 2004. Murray et al., 2002). The same findings were reinforced with pooled results through a review of the literature by the same authors on dying trajectories in those with chronic progressive illness (Murray et al., 2005). Murray's study above also gave depth to the disease trajectory by detailing the nature of the distress caused by the functional decline and gave insight into planning care based on patients' priorities at different stages. Conversely, Gott et al. (2007) using QoL instruments reported finding no clear trajectory pattern emerging from the majority of their HF participants. Only six patients out of the 27 patients in their study fitted the typical theoretical organ failure dying trajectory described by Lunney et al. above (Gott et al., 2007). Their findings however were limited because, as noted by these authors, they had a sample size of 27 which may be too small to detect a clear difference using instruments, and alternative patterns might have emerged from a larger sample.

The concept of the illness trajectory has limitations and it is recognised that every person with HF will have a different course of the illness confounded by the aetiology of the HF and presence of co-morbidities. However, many patients do appear to have a similar pattern of gradual decline interspersed by episodes of acute deterioration and in time a seemingly unexpected death, or death due to progressive HF (Murray et al., 2005). The majority of HF patients appear to go through three stages: a chronic disease management phase (NYHA I-III) which is the first stage where they are relatively stable and need regular chronic disease management; a stage of secondary decline requiring increased use of hospital care and a variety of supportive and palliative care strategies; and finally, a tertiary terminal phase of inevitable decline lasting days or weeks (Jaarsma et al., 2009. Murray et al., 2002).

Kheirbek et al (2013) in a more recent study, advanced the concept of dying trajectories in HF by taking into account the patients' comorbidities when charting their illness trajectory (given the findings from previous studies that comorbidities in HF influenced the trajectory of illness). Kheirbek et al. used retrospective data of 386 decedents and chose those records that had five data points in the last 12 months of

the decedents' lives for their sample. They then used trajectory modelling to analyse their findings. Their findings identified five trajectories of dying with HF. These included: (1) unexpected death (20.5%) which they defined as a trajectory where patients had moderate risk of dying at time point one (when first presenting to health care) but chance of death increased by 20% at point five; (2) the rapid progression trajectory, (13%) where patients had no risk of death in the first six months but this risk increased in last 6 months; (3) the late progression trajectory (36.3%) where risk of death increased in the last 3 months; (4) the early progression trajectory (13.3%) where patients had low initial risk but risk increased in the first nine months; and (5) the constant high-risk trajectory (16.9%) where patients had a high risk of dying all the time (Kheirbek et al., 2013). The results of this study are not directly comparable with those in the previous studies because this study tried to project prognosis and risk of dying using patients initial diagnosis, the presence of co-morbidities and patients' physical functional status over time. Then they compared their initial projected prognosis with patients' actual time of death. Their study is useful in illustrating how other factors such as co-morbidities may influence the illness trajectory and it provided more analysis into this subject by comparing anticipated risk with actual risk. The weakness of their study was in the use of retrospective data and the possibility of selection bias because they had to get decedents' records that had five data points and excluded others who may have had different trajectories.

It appears from the above findings that there is a typical HF trajectory that most patients have, but this will be influenced by co-morbidities. These results, however, are all from high-income countries where disease aetiology differs from low-income countries and where availability of medicines and patient follow-up care for HF is not as challenging.

2.1.2 Physical needs and issues in the heart failure experience

The literature on physical needs in the experience of people with HF is centred on the following themes; symptoms in those with HF and their effect on physical function and impact of co-morbidities on symptoms.

Symptoms in heart failure

Symptoms are defined as the perceived changes in normal functioning or appearance (Henly et al., 2003). Symptoms in HF are becoming of increasing interest partly because they limit self-care that is important for better outcomes (Riegel and Carlson, 2002), but also symptoms that are directly related to HF have prognostic significance. The prognostic significance of symptoms was demonstrated in the COMET trial (Ekman et al., 2005) where it was found that patients' self-assessed symptoms were predictors of outcomes such as survival and hospitalisation. Patients with breathlessness were 1.14 times more likely to die as compared to those without it, (RR 1.14; 95% CI 1.04-1.26; P =0.01) and HF patients with fatigue were 1.09 times more likely to be hospitalised compared to those without it. (RR 1.09; 95%CI 1.02-1.17; P =.02). Although the risk ratios quoted in this study are very close to the neutral of one, these results by virtue of their p value of less than 0.05 show that they are significant. Ekman et al.'s findings from the COMET trial are supported by findings from Hertzog, Pozehl and Duncan's (2010) study who found that patients with increased distress from the "weary symptom cluster" (lack of energy, lack of appetite and difficulty sleeping) were 1.45 times more likely to be re-hospitalised, than those without these symptoms (HR 1.45 95%CI 1.09-1.93). In the same study patients with increased distress from the "dyspnoea symptom cluster" (shortness of breath, difficulty in breathing when lying flat and waking up breathless at night) were two times more likely to have cardiac mortality (sudden death) in 12 months than those without it (HR 2.00; 95%CI 1.16-3.34) (Hertzog, Pozehl and Duncan, 2010). This study showed that the impact of symptoms was even greater when they were occurring as clusters and these findings were echoed by Moser et al. (Dekker et al., 2014).

Several studies have demonstrated that patients have multiple symptoms. Moser et al. (2014) in a multicentre and multicultural study of symptoms in HF found that HF symptoms occur in similar identifiable clusters in different cultures and, therefore, the presence of one should trigger identifying other symptoms in patient assessments. Other studies have also shown that HF patients have both HF and non-HF symptoms. Anderson et al. (2001) using a comprehensive checklist, identified the following symptoms and their prevalence in HF patients: breathlessness 53%; angina 32%; tiredness 82%; difficulty walking 65%; pain 41%; dry mouth or thirst 45%; loss of appetite 21%; constipation 12 %; shortness of breath 83%; nausea or vomiting 17%;

difficulty sleeping 48%; bladder or bowel control 11%; cough 44%; sweating 32%; swallowing problems 5%; decreased sexual interest 42%; unpleasant smell or discharge 8%; and swollen arms/legs 33%. This study's strength was in utilising quantitative (check-list) and qualitative data collection methods (open questions that facilitated in-depth understanding of the symptom experience) The study highlighted that the most prevalent symptoms were not necessarily the most troublesome. It was noted in this same study that physicians mostly paid attention to cardiac symptoms and rarely non-cardiac symptoms and therefore rarely treated the non-cardiac symptoms (Anderson et al., 2001. Janssen et al., 2011), findings that were similar to those of Janseen et al.(2011). Pain, which is often considered a general symptom had a high prevalence in HF estimated at 60% in one study, but it was found to be under-reported by healthcare professionals (Shah et al. 2013). A similar symptom profile as that in Anderson's study was also found by Albert et al. (2010), however the latter's study went further in illuminating the understanding of the symptom experience by studying the relationship between symptoms, demographic factors and the context. They showed that symptoms differed with age, gender and race and those symptoms changed in those at home and in the hospital (Albert et al., 2010). A gap in this study was its failure to note how these symptoms changed in the hospital and at home for the same person. Walke et al.'s (2007a) longitudinal study demonstrated the temporal trends of symptoms. They observed that physical discomfort and fatigue were most common towards death and two-thirds of the patients reported shortness of breath, problems with appetite and pain. Walke et al.(2007a) also found that the symptom burden increased over time, but surprisingly from their study, there was no significant association between the symptom burden with number of co-morbidities and with whether the participant died (Walke et al., 2007a). The percentage of patients reporting shortness of breath, pain and fatigue increased over time and pain showed the greatest increase in severity over time (Walke et al., 2007a). This may be explained by the cause of HF in this setting, which is ischaemic heart disease, which is often associated with ischaemic pain. The prevalence of pain was anticipated to be lower in Uganda due to the lower prevalence of ischaemic heart disease in the country. Pain however may have multiple causes in HF, for example, it has been associated with a lower ejection fraction (Shah et al., 2013).

In addition to identifying the common symptoms described in quantitative studies, several qualitative studies added to the understanding of the symptom experience by unveiling uncommon and atypical symptoms in HF. The qualitative studies also demonstrated how meaning attached to symptoms impacts patients' lives and behaviour. Two studies found that although symptoms were important in triggering the seeking of medical care this did not happen if symptoms were thought not to be related to HF or if they were believed to be due to co-morbidity (Rogers et al., 2002. Riegel and Carlson, 2002). Gallagher et al.'s study (2012) ably illustrates this in their findings that patients experienced up to seven symptoms before their first hospitalisation and less than half of patients contacted a health professional before hospitalisation. The triggers for seeking early care in their study were having symptoms such as chest pain, a change in symptoms and if symptoms occurred after midnight. They also observed that more than 50% of admissions could be avoided by early detection of symptoms (Gallagher et al., 2012). Falk et al. (2013) found that older age influences interpretation and reporting of symptoms and ultimately the seeking of care. Boyd et al. (2004) added another layer to the understanding of symptoms by weaving the importance of meaning attached to the symptom and the relationship between symptoms and co-morbidity in the symptom experience. They showed that the meaning attached to symptoms influenced one's social life and self-perception. They also highlighted the additive effects of co-morbidity and treatment-related symptoms in the HF experience, and the relationship between symptoms such as that between anxiety and breathlessness. Their study also noted symptoms that had not been identified in other studies such as sleeplessness which impact on one's life. This study identified unique findings from other studies and this may be attributed to the use of qualitative longitudinal methods that allowed in-depth understanding. Their study, however, was not clear on how patients' symptoms changed over time (Boyd et al., 2004). Horne and Payne's study (2004) demonstrated that symptoms had an impact on physical functioning and they identified symptoms that had not been found in other studies, such as weight loss and other symptoms which they termed 'atypical' including loss of consciousness, faintness, and dizziness (Horne and Payne, 2004). They, therefore, raised awareness to the broad spectrum of possible symptom in HF.

Co-morbidities

Co-morbidity is having one or more other illnesses that affect the management of HF (Jeon et al., 2010). The co-morbidities identified from previous research include depression, diabetes, asthma, arthritis, diabetes (which was the commonest), high blood pressure, arrhythmias, pneumonia, arthritis, degenerative spine disease and bleeding ulcers, lung disease, arthritis, visual impairment, deafness, liver and renal problems, cancer, cerebral vascular disease, myocardial infarction and anaemia. (Jeon et al., 2010. Riegel and Carlson, 2002. Boyd et al., 2004. Dahlström, 2005. Janssen et al., 2011).

Several authors have elucidated the importance of understanding the interaction between co-morbidity and HF and how this may affect the illness experience as described below. Co-morbidity was found to contribute to the symptom burden in HF and was sometimes more troublesome than HF itself (Boyd et al., 2004. Dahlström, 2005). Co-morbidity also delayed and complicated the diagnosis of HF and the treatment and care experience by increasing the treatment and care burden (Phillips, Marton and Tofler, 2004). Co-morbidity also led to increased mortality at an earlier date, and was related to old age (Chaudhry et al., 2010). To note is that a different burden of co-morbidities was found in Africa in the THESUS-HF, where there were more patients with HIV/AIDS (13%) than diabetes (11%) (Damasceno et al., 2012).

2.1.3 Social needs and experiences

The importance of the social experience in illness is highlighted by Costello and Boblin (2004) who demonstrated that the psychosocial impact outweighed the physical impact in patients with HF. The psychosocial impact of HF becomes more prominent later in the disease trajectory as evidenced by Murray et al. (2007) who noted that social needs worsened with physical decline. The main theme in the literature on the social experience of HF is life-disruption, with sub-themes of social isolation, relationship issues and financial consequences.

Life disruption

HF leads to a major shift in the sufferer's plans and dreams for their life, their relationship with others and their day-to-day activities. Hopp et al. (2012) defined life disruption as: "*the ways in which HF is experienced as an abrupt transition from a person's previous way of living*" (p157). In a qualitative study involving 35 African

Americans with HF, Hopp et al. (2012) demonstrated that life disruption was a major experience and was characterised by limitations in activities, making sense of HF and often led to psychological consequences. These authors also found that following life disruption, patients used several strategies to continue living and described coping mechanisms they used such as drawing on previous resilience and spirituality. Hopp et al.'s study (2012) was, therefore, consistent with Bury's theory of biographical disruption and coping (Bury 1991). A review of the literature by the same authors on the experience of HF patients cited life disruption as a common experience from several studies, with patients no longer able to engage in previous favourite activities (Hopp et al., 2010). Freydberg et al. (2010) clearly showed how context and the values people hold are important in the people's definition of life disruption. In their qualitative study of a rural population in Canada, life disruption was synonymous with disruption to work. This was because of the value that was placed on work in that community who considered work pleasurable and vital in their lives and was related to meaningful existence. Work also defined their identity as farmers and identified them with their community (Freydberg et al. 2010). These two studies give useful insights into disruption and the role of context and values in this concept, however they could have been improved by using a longitudinal design to enable understanding of how the concept of disruption evolves across the illness trajectory as physical function deteriorates further.

Dependence

The literature revealed that dependence was a common consequence of loss of function in HF. Dependence appeared to be more frequent in the elderly as people became unable to carry out tasks essential to household management (Falk et al., 2013). However, most studies that were reviewed were from high-income countries where HF is a condition mostly of the elderly and this could have influenced this finding. Waterworth and Jorgensen (2010) studied the transition to dependence for 25 older patients with HF using qualitative longitudinal interviews. They found that as patients became more dependent as they deteriorated, they expressed concern and fear of being a burden, and some even wished for death in the event that they became dependent. The fear of dependence seemed to worsen when patients became completely dependent despite good care. This study's longitudinal design facilitated an understanding of patients' views on dependence before and after it happened. Falk

et al. (2013) demonstrated that people employ behavioural changes to facilitate the shift from being independent to being dependent. These include adjusting to activities and being creative by accepting to do daily activities in collaboration, which then helps them to accept their situation (Falk, Wahn and Lidell, 2007). In one study, patients had to make trade-offs to maintain independence by accepting the use of assisted devices which they did not like (Lowey et al., 2013). The importance of independence to individuals, appeared to be related to their view of what is a 'valuable life' as demonstrated in several studies that showed that dependence led to participants questioning their value and worth and feeling useless and was a source of frustration (Murray et al., 2007. Ryan and Farrelly, 2009. Leeming, Murray and Kendall, 2014). The inability to do personal care such as bathing oneself also led to a loss of dignity (Boyd et al., 2004).

Social isolation and the need for support groups

Social isolation was also a common finding among HF patients. Social isolation was mainly caused by physical decline, but was compounded by a changed self-image, medications which caused increased urination, and difficulties planning toilet breaks and social events due to the unpredictable illness (Leeming, Murray and Kendall, 2014). Social isolation was often associated with psychological consequences. Participants, particularly those who were housebound, described how they became lonely and lost and depended on others to stay connected to the world (Hopp et al., 2010). In Jeon et al.'s review (2010), participants struggled with isolation and felt abandoned and sometimes misunderstood by family and friends. Participants in two studies felt they had been written off and social isolation led to frustration and low mood with decreasing self-confidence (Jeon et al., 2010. Boyd et al., 2004. Murray et al., 2002). Participants and their carers were cut off from activities they had enjoyed in the past because of the illness. For some, it felt like being incarcerated and led to wishing for death. Patients' social struggles were aggravated by their carers' surveillance over their lives (Ryan and Farrelly, 2009). Men were more likely to experience isolation and loss than women (Costello and Boblin, 2004). Support groups were suggested as a means to overcome this isolation and for encouragement to adhere to self-care and participate in family and social activities and get jobs as appropriate (Falk, Wahn and Lidell, 2007. Liljeroos et al., 2014. Heo et al., 2009a). However, others rejected the idea of support groups because sharing experiences,

especially with those not close to the participants, represented a loss of control and identity (Jeon et al., 2010).

Emotional isolation was also common and resulted from negative relational experiences with those close to them. These negative experiences included not being taken seriously by friends and family (who did not recognise the gravity of their problem because sometimes the HF signs were invisible) and decline in sexual interest, performance and intimacy, especially among male participants (Boyd et al., 2004, Nordgren and Fagerberg, 2007, Jeon et al., 2010). Strengthened family relationships resulted from patients' partners participating in management of their condition (Jeon et al., 2010) and when friends and neighbours supported them in the day to day living (Welstand et al., 2009), protected them from emotional isolation and facilitated adjustment to life with HF and coping (Thornhill et al., 2008. Sacco et al., 2014). These studies highlight the multifaceted nature of isolation and its relationship to life disruption and relationships. These studies employed appropriate methods of investigation, however, these studies were done in a context where the culture of individualism and small families exist. An understanding of this theme of isolation in Africa, where extended families and communities are part of one's daily life, is important.

Financial needs

Financial struggles and the need for financial support were only occasionally expressed in patients' experiences in the literature from high-income countries, depending on the health service cost sharing model. Financial struggles resulted from the multiple clinic appointments, multiple hospital visits and hospitalisations which were aggravated by poor communication between the primary-secondary care interface (Gallacher et al., 2011). Financial concerns were prevalent among those who were no longer able to work and these financial struggles affected patients'coping mechanisms (Pattenden, Roberts and Lewin, 2007). In one study in the USA, economic problems led to patients not being able to afford their medications and this affected their QoL (Heo et al., 2009b).

2.1.4 Psychological needs and experiences

In most studies, it was noted that psychological needs were not often assessed and, therefore, were not addressed. The literature on the psychological experience of

patients with HF revealed two common themes: psychological responses to the illness (symptoms) such as anxiety and depression and psychological adaptation.

Psychological symptoms

Studies that explored psychological symptoms in HF patients employed either quantitative or qualitative approaches. Quantitative studies revealed that anxiety and depression are highly prevalent in patients with HF and described factors that are associated with psychological symptoms. The prevalence of depression in a meta-analysis of various studies was found to range from 9% to 60% and was higher in patients with NYHA III and IV. In patients attending an outpatients HF clinic in Nigeria, the prevalence of anxiety and depression was 16% and 13% respectively and 39% had both anxiety and depression (Ansa et al., 2009). Anxiety and depression were found to coexist in some patients with HF and depression was a strong predictor of anxiety in HF patients (Anderson et al., 2001. Dekker et al., 2014). Anxiety and depression were found to be more prevalent in younger patients than older patients (Costello and Boblin, 2004. Dekker et al., 2014). Depression was associated with poor quality of life, younger age, unemployment and being unmarried in another group of patients in Nigeria with HF (Ola et al., 2006). Qualitative studies were useful in giving clarity to what influences relationships between the psychological symptoms and those factors associated with them. Anderson et al. (2001) in a mixed methods study, found that although all HF patients disclosed their psychological problems to their health professionals, these were acted on by the health professionals in less than half of cases. This study showed differences in patients and health professionals' priorities of what was considered as distressing symptoms. Studies by Riegel and Carlson (2002) and Horne and Payne (2004) found the common psychological symptoms to be anxiety, panic, depression, worry, being sad and frightened. For some participants, these symptoms were in response to increasing disability (Riegel and Carlson, 2002. Horne and Payne, 2004). Participants were afraid of pain, death, safety, not being able to work, recurrence of a heart attack and rehospitalisation (Horne and Payne, 2004. Ryan and Farrelly, 2009. Jeon et al., 2010). The fear of dying was more common in women and the fear of inability to work was more common in men, but the men also became more fearful of death as the illness progressed. The men also tended to be more pessimistic about their illness but women were more optimistic and accepting (Jeon et al., 2010). The grave terms participants used to describe the effect of HF on their lives such as 'shattered', 'rotten' and

'absolutely unreal' reflected their emotional distress. These patients did not always discuss their feelings with their families to protect them, although they felt the need for emotional support, the lack of which compounded loneliness (Horne and Payne, 2004). Strong social support protected patients from psychological distress, while baseline distress, emotional problems and disease severity predicted distress at follow-up (Scherer et al., 2007). Anxiety was exacerbated by physical deterioration and physical limitations and social isolation led to frustration and low mood (Murray et al., 2007).

The literature showed that there were trends of psychological well-being over the course of the illness. Walke et al. (2007a) in a longitudinal study found that one-third of HF patients reported anxiety and up to one-half reported feelings of depression in the final review after a median follow-up of 22 months. The percentage of patients reporting depression increased significantly over time. Anxiety in this study was as prevalent in the first and last interviews (Walke et al., 2007a). These findings were surprising given that symptoms such as breathlessness increased in prevalence over time and these are known to be associated with anxiety and panic (Boyd et al., 2004). Murray et al.'s qualitative longitudinal study (2007) was useful in illuminating the relationship between different multidimensional experiences and how psychological well-being tended to mirror physical and social trajectories over the course of the illness. The literature revealed that the understanding of psychological symptoms is enhanced with the use of both quantitative and qualitative approaches, which give breadth and depth to the subject. The literature on psychological symptoms included studies from Africa. However, all the studies from Africa were quantitative and therefore they do not give in-depth understanding of these symptoms in Africa, which has a different cultural and social context that may affect the expression of psychological symptoms, thus, the need for a qualitative study on the subject in Africa.

Living with Loss

The experience of loss was a significant theme in the literature on experiences of living with HF. A common loss expressed was the loss of identity, with patients feeling they were no longer the person they used to be because of their loss of function, increased dependence and loss of roles that they had treasured in their lives (Leeming, Murray and Kendall, 2014). People felt that giving up precious things that made life meaningful fostered feelings of frustration and personal failure (Nordgren,

Asp and Fagerberg, 2007). Jeon et al. (2010) described how participants lost a sense of control when they perceived they had no power and capacity to influence their life or illness. This loss of control was associated with an unpredictable decline in health, loss of independence and financial security, not participating in management decisions, restrictions imposed on their lives due to treatment and relocation from their homes. This resulted in feeling helpless and powerless (Jeon et al., 2010). Patients who felt they had a sense of control from taking responsibility for lifestyle changes felt a sense of transcending the illness and felt more satisfied and it was a source of inspiration. Patients gained control of their illness by acquiring knowledge of how it is likely to progress (Jeon et al., 2010). Participants tested the limit of their bodies in an attempt to master their bodies as a means of gaining control of their illness and tried to work within these boundaries (Nordgren, Asp and Fagerberg, 2007).

The studies reveal a complex interplay of multiple losses in HF. Loss of control appeared to be the most significant loss that impacted the HF experience. The findings may reflect the populations studied that were from high-income countries where being in control is a highly valued attribute. There was no mention of including less affluent communities from these studies' inclusion criteria. Less affluent communities tend to be more resigned and accepting of life's problems and tend to have a 'fatalistic' interpretation of life events and in Africa surrendering to the Divine is common and therefore it is important to understand what the most significant loss is for the populations in this study.

2.1.5 Spiritual experience and needs

The importance of the spiritual experience and its impact in HF has been highlighted in several studies mostly based in high-income countries. Spiritual well-being was found to be associated with a positive illness experience in HF and spiritual distress was associated with a negative experience. Patients with greater spiritual well-being, in particular, those who found meaning and peace in the experience, were found to have less depression and less death anxiety (Bekelman et al., 2007. Sacco et al., 2014) Spirituality helped patients in coping with HF as they reported faith and spirituality as a source of great comfort (Welstand, Carson and Rutherford, 2009). Spirituality also fostered resilience by nurturing a new way of living with greater meaning and

willingness to adjust along with developing an attitude of gratitude (Hopp, Thornton and Martin, 2010). Other positive experiences fostered by spirituality from Murray et al.'s study (2007) were love, hope, trust and forgiveness. Hope was enhanced if participants accomplished even small goals such as having a walk, and participants moved between hope and hopelessness time and again (Murray et al., 2007).

Spiritual distress was also commonly described and frequently manifested in physical and psychological symptoms such as anxiety, panic attacks and depression. Failure to articulate this distress, or failure of health care workers to hear the nature of the distress being articulated often led to mislabelling of patients as depressed resulting in mismanagement and more hospital visits (Grant et al., 2004). Other negative spiritual experiences included a sense of existential hopelessness and uselessness, a wish for death, a struggle to find meaning and one's identity along with feelings of being punished by God (Grant et al., 2004. Ryan and Farrelly, 2009). Boyd et al.'s study (2004) identified feelings of loss of dignity because of having to depend on someone for bathing and other activities of daily living, loss of autonomy and self-esteem. Loss or compromise of the participants' satisfying roles in life was the main reason for the loss of self-esteem. They hoped for the present situation to be temporary, a better future, positive change and a meaningful and purposeful life (Nordgren, Asp and Fagerberg, 2007).

Beery found that spiritual needs included participation in religious activities and attending to patients' spiritual needs was rated as of moderate to high importance to their QoL. While assessment of spiritual needs was not the aim of the study, it emerged because of patients' repeated responses that featured it as important (Beery et al., 2002). Similarly, in another study that aimed at exploring the perceptions of patients with HF about QoL, patients mentioned faith and praying to be important to QoL, and some patients actually stated that it was the most important thing (Heo et al., 2009a). Patients expressed a need for peace of mind, freedom from fear of death and the unknown and the need for a guide into the unknown (Boyd et al., 2004. Grant et al., 2004). The necessity of respect was illustrated by the finding that being affirmed and valued by doctors enabled participants to come to terms with the illness and retain a sense of worth and meaning (Grant et al., 2004). Ross and Austin (2015) found that spiritual needs for HF patients in Wales included the need for love and belonging, the need to keep hope alive, the need to find meaning and purpose in

illness, and the need for spiritual support. The longitudinal study by Murray et al. (2007) illuminates the trend of spiritual well-being in the course of the HF, which was described as gradually decreasing in the course of the illness. This was attributed to the loss of identity and growing dependence that led to patients questioning their value and meaning in the world (Murray et al., 2007). Some studies have suggested that HF patients who engage in spiritual practice and have religious meaning in their life are more realistic over the estimates of their longevity and have better adherence to therapies with risks (Naghi et al., 2012). Spiritual care appears to have a positive impact on one's quality of life (Tadwalkar et al., 2014). With strong spirituality (mostly expressed in religion) a marker of many African communities, it is important to find out how these trends develop and change in the African context.

2.1.6 Information needs

Several studies from high-income countries demonstrated that patients have unmet information needs. Compared to cancer patients, HF patients did not remember getting any written information and, therefore, had poor understanding of their condition and the associated symptoms (Murray et al., 2002). Participants reported having conflicting and incorrect information that led to unconventional self-care and worsened symptoms (Riegel and Carlson, 2002). Several studies showed that patients needed information on the disease symptoms, treatments, how to cope, prognosis and dying and wanted information to be given sensitively (Murray et al., 2002. Rogers et al., 2002. Horne and Payne, 2004. Harding et al., 2008. Gallacher et al., 2011). Patients and their carers felt that receiving information regularly and addressing their questions made them feel in control of their HF (Liljeroos et al., 2014). Family conferences and access to advice on the phone were suggested by patients as means to improve giving information (Harding et al., 2008). Barriers to the provision of information included difficulties in prognostication, cognitive problems in the patients, lack of empowerment of the patients to ask, lack of insight into what to ask and a lack of skills and time from the health professionals. Cardiologists felt the need to maintain hope for the patients by not giving full information to the patients but giving it to their carers. Lack of information was found to contribute to anxiety, frustration, depression, inability to plan appropriately, unrealistic expectations and poor drug adherence (Harding et al., 2008). Some participants felt they should not ask

questions of their health professionals and some felt the health professionals limited the amount and the nature of information provided (Wingham et al., 2014).

2.1.7 Self- care

The European Society of Cardiology guidelines for the management of HF define self-care as "*actions aimed at maintaining physical stability, avoidance of behaviour that can worsen the condition, and detection of early symptoms of deterioration*" (Dickstein et al., 2008, p946). Self-care behaviours include understanding of HF, its symptoms and treatments and adhering to recommendations on risk factor modification that include recommendations on appropriate diet , exercise, sexual activity, immunisation and sleep. Self-care is recommended by the guidelines as one of the key elements in the management of HF. Patient self-care is vital for the successful management of HF and can influence symptoms, functional capacity, well-being, morbidity and prognosis (Dickstein et al., 2008). The literature reveals that although self-care is recommended and patients recognise it as important, it is not always adhered to because of various factors in the illness experience. Riegel and Carlson (2002) highlighted the barriers and facilitators of self-care in HF in 26 individuals using in-depth interviews and focus groups discussions. They found that barriers to self-care included physical limitations, side-effects of treatment which affected their day-to-day life, misconceptions about the disease and its treatments (which resulted from lack of knowledge) and co-morbid conditions which complicated the treatments and behaviour recommendations. Patients were able to recognise the classic symptoms of HF as an indication of seeking medical help, although presence of co-morbidity sometimes led to delayed association of the symptoms with HF as the symptoms initially were attributed to the co-morbidity. The conflict in the lay knowledge patients had on HF and how to care for self and what was being recommended by health professionals led to confusion among patients. For example traditionally when one is ill, rest is recommended or one is required to increase fluid intake yet HF patients were told by health professionals to exercise and limit fluid intake. Patients sometimes chose to adhere to treatment and behavioural recommendations depending on how they best suited them and their wellbeing. Also, patients did not comply with recommendations if they thought that these recommendations were not related to their HF symptoms and if they doubted whether they would influence their condition.

Sheahan and Fields (2008) found that the lack of appropriate information, eating alone with no motivation to cook and sharing meals were barriers to taking a salt-restricted diet. Barriers to physical activity included symptoms, co-morbidity, a poor sense of self as an active person and a lack of perceived benefit (Tierney et al., 2011a). Older age tended to be more associated with lack of knowledge and cognitive abnormalities that could have been responsible for poor self-care among this age group (Falk et al., 2013). Dietary challenges were also identified as being a common barrier to self-care (Woda et al., 2015).

Facilitators to self-care in Riegel and Carlson's study included having memory aids to help them with taking their drugs, fear of the doctor's reaction, others felt self-care was an opportunity to improve their health ,that they did not want to waste. In order to perform self-care, some patients had to adapt by modifying their environment and their activity based on their functional capacity. Learning about the illness facilitated self- care (Riegel and Carlson, 2002). The need to stay out of hospital was the main motivator to take on self-care, but also the realisation that the outcome depended on them and the need to be in control of their lives (Riegel and Carlson, 2002. Lowey et al., 2013). Other facilitators included getting information from their professional carers, emotional support from all carers and friends, tangible support from health professionals, family and community. Encouragement from others and family also facilitated physical activity and other self-care (Tierney et al., 2011b. Wingham et al., 2014). Recognition of changes in symptoms also prompted self-care in patients in Egypt (Samir and Nour, 2011).

In a review of qualitative studies of patients' and carers' experiences of self-care, Clark et al. (2014) found that there were deficits in knowledge of self-care. Integrating self-care into daily life improved adherence to it and carer support nurtured patient independence. Predictors of better self-care include the presence of more comorbid conditions, a stronger sense of coherence and good adherence to self-care (Gallagher, 2010). Wingham et al. (2014) from a meta-synthesis of qualitative research elucidated self-care as a process and explained that different factors interplay to lead to the development of self-management strategies. They described patients going through various stages before the development of their self-management strategies. These stages include experiencing disruption before making sense of HF, this is followed by different reactions which include: the strategic avoider who leaves

most of his care to his professionals and carers; the selective denier who although recognises that HF is a serious condition denies the personal significance of the condition; the well-intentioned self-manager who is highly motivated to adopt a broad range of self-care activities but these are based on misconceptions and a lack of knowledge; and finally, the advanced self-manager who uses formal knowledge appropriately. Reactions are followed by patients' responses of forming self-management strategies that are then assimilated into their daily life (Wingham et al., 2014). Most of the above studies of self-care were done at a single point in time, but Wingham et al.'s findings (2014) show that self-care is an evolving process and this was not demonstrated in the above studies, highlighting the need of longitudinal studies in this area.

2.1.8 Experience of the treatments

Burden of treatment

The literature revealed that treatment of HF puts an extra burden on HF patients attributed to the number of pills they have to take, the side-effects of the drugs and all the work and lifestyle adjustments demanded (Wingham et al., 2014). In Boyd et al.'s study (2004), participants reported having to endure increasing doses and types of medications and balance it with having to take extra fluid despite the recommended fluid restrictions. Participants felt that with the medication they traded one problem of getting rid of disease symptoms with others associated with the treatment. Their findings were in line with those in Rogers et al's study (2002) where participants reported taking between 1 to 21 tablets each day and were concerned about the high dosages and the combination of drugs they were taking as they often conflicted with the leaflets that were in the drug packages. In a secondary analysis of qualitative data of 47 patients, the burdens associated with treatment for HF included time and effort learning about the treatments and their consequences, getting others involved in getting the treatment and to give specialist advice and changes one had to undertake to adhere to recommended medications and lifestyle changes. Participants reported that working through treatment regimens and their side-effects cost a lot of time and energy. They had to titrate treatments to fit their activities and often kept assessing and adjusting these treatment plans alone or with others (Gallacher et al., 2011).

Adherence to treatment

The literature revealed varying levels of adherence to HF treatment and motivators and barriers to treatment adherence. Bhagat and Mazayi-Mupanemunda (2004) found that 27% of patients with HF in Zimbabwe were not compliant to treatment despite having been given 30-minute sessions of verbal information followed by written information about the drugs. Some of the patients in their study did not often recall their medication types or schedule even after having had the condition for an average of 43 months (Bhagat and Mazayi-Mupanemunda, 2004). Thus their study shows that it is not enough to give information, but it is important to find out how it is processed. The limitation of their study was that they did not explore other factors, apart from information, that may influence adherence to treatment. Riegel and Carlson's qualitative study (2002) of 27 HF patients looked at the factors that influence treatment adherence. Participants in their study reported that they purposely skipped those medications, which caused undesirable side-effects in public, if they had scheduled activities (Riegel and Carlson, 2002). Facilitators for adherence to medication included: desire and hope of getting well; use of memory aids; making the doctor happy; recognising it was the only way out; some just did what was told to them; and, fear of being hospitalised. Most patients in Riegel and Carlson's study (2002) reported to be mostly compliant with their medications, but these patients had participated in other HF studies and their responses may have been influenced by their experience in research and they would have given the researcher the response that they thought was required. Horne and Payne (2004) and Wingham et al.'s (2014) studies also contribute to understanding the factors that influence adherence. In Horne and Payne's study participants adhered to treatment if they felt the medications were important for their survival, but others, who considered them to be a bother because of the unwanted side-effects, did not adhere to treatment. Patients were also anxious about the changing doses and feared to run out of options of treatment in the future. They often negotiated with their doctors to reduce or stop the drugs and if they did not succeed they did it themselves (Horne and Payne, 2004). Compliance was better in those with a positive attitude and those who had poor compliance rationalised treatment as unimportant, difficult to follow and ineffective (Wingham et al., 2014). These studies, therefore, demonstrate that adherence is influenced by a complex interplay of factors determined by how patients interpret the usefulness of the medications and how the prescribed regimen fits into their daily lives. How people

interpret information and how people live are influenced by one's culture and social circumstances. Since the above studies were done in Western culture, there is need for information in this in an African context with a different culture.

2.1.9 Quality of life

QOL is an important goal in the care of those with life-limiting illnesses such as HF. QOL is known to be a subjective concept best determined by the one suffering from the condition. This concept was clearly demonstrated in a qualitative study of 20 HF participants carried out by Heo et al. (2009a), which elicited patients' perspectives on the concept. They found that being able to perform physical and social activities, maintaining happiness, being satisfied with life, and engaging in fulfilling relationships, were important concepts in patients' definition of QOL (Heo et al., 2009a). Thus, they showed the multifaceted nature of QOL. They also demonstrated that multidimensional factors including physical, psychological, social and spiritual, affect QOL either negatively or positively. Their comprehensive study found that patients' rating of their QOL was determined by their expectations, comparison with others ability to do desired activities, and having survived worse situations. They, therefore, conclude that patients' perceptions of their QOL reflect their adopted view to their changed clinical condition and their positive attitude (Heo et al., 2009a). Moser et al. (2013) explicate the importance of patients' expectations and their adopted view of their clinical conditions through a mixed methods study involving 20 patients both young and old. They demonstrated that elderly patients rated their QOL as high compared to that of young people, despite having disability because for the elderly their QOL exceeded their expectations for their age but the young ones expected better (Moser et al., 2013). Falk et al (2013) also echoed these findings and observed that participants' QOL depended on their expectations, if they had unfinished business, whether they felt happy despite the circumstances, and how participants viewed themselves in comparison to patients they had seen who were worse than them. Other factors that have been shown to influence QoL include: physical symptoms; role loss; affective response; coping; presence of depression; lack of energy; social support; family concerns; cognitive function; and uncertainty about the prognosis (Bosworth et al., 2004. Ryan and Farrelly, 2009. Årestedt et al., 2013. Hwang, Liao and Huang, 2014). These studies, however, were cross-sectional and

because they infer an evolving patients' perception of QOL, qualitative longitudinal methods could elucidate this concept further.

2.1.10 Coping

People respond to the changes that HF imposes by using different coping mechanisms to help them live with these effects. Research shows that some coping mechanisms are strong and enduring over the illness course but others weak and are not stable. Boyd et al. (2004) described this in their qualitative longitudinal study. They noted that participants coped emotionally by having a positive attitude and sharing experiences with spouses and family and that this brought them closer and strengthened their relationships. Weak coping mechanisms in their study included the use of humour, a determination not to be beaten, pragmatism and stoicism (Boyd et al., 2004). Other studies identified other coping mechanisms employed by patients such as resilience; self-care; spirituality; pacing activities; learning about HF; getting emotional and practical support from family, friends and health professionals; ignoring the problem; withdrawing; and acceptance (Riegel and Carlson, 2002. Hopp et al., 2012). The coping mechanisms employed were an indicator that one had adjusted or had not adjusted to living with HF and thus determined peoples' QoL. Yu et al. (2008) and Graven and Grant (2013) in their reviews of the literature showed that emotional coping strategies such as avoidance and denial were negatively associated with psychological HRQoL and practical coping strategies such as seeking social support and problem-solving were positively associated with psychological HRQoL. Appropriate adjustment happened if patients could make sense of their illness, accept the prognosis and get on with living with the illness (Yu et al., 2008, Graven and Grant, 2013). To note, acceptance was the only emotional coping mechanism that resulted in appropriate adjustment (Yu et al., 2008). Coping was also found to occur at multidimensional levels including the psychological, physical and spiritual. Physical coping resulted from adjusting to new circumstances by slowing down (Jeon et al., 2010), or by reorganising their lives to fit around the activities they valued the most. Psychological and spiritual coping resulted from: remaining positive by accepting the situation and "making the best of it"; experimenting on themselves to find out what worked best; getting more information; and employing faith and spirituality (Welstand, Carson and Rutherford, 2009). Hopp et al.'s study (2012) was the only one that demonstrated that the choice of the coping mechanisms employed may be influenced by factors such as culture and past

experiences. They worked with a different ethnic and culture group of African Americans, and found that although this group had similar coping mechanisms to those in the literature from Caucasian patients, such as employing faith and spirituality, they also had a unique coping mechanism, which was resilience that they had built up from previous experiences.

The literature also revealed that there are factors that enable and disable coping leading to feelings of security or insecurity respectively. Burstrom et al (2012) in a focus group discussion with 8 women with chronic HF aged 76-88 years, showed that the following enabled coping: acceptance of their past, everyday life and the future; having a reasonable level of physical functioning despite their illness; symptoms not severe; adjusting to life with the symptoms; having social support from family and friends; having the health professional readily accessible; and having faith in the treatment given to them. The following hindered coping: feeling guilty about the disease due to past behaviour or self-blame; trying to prove to others that they still can perform their roles but failing to do so; physical limitations due to symptoms; a lack of understanding of why the symptoms were occurring; difficulty managing lifestyle restrictions such as fluid intake; anxiety about being dependent and isolated; thinking death was imminent; lack of faith in treatment; and, worry about drug side-effects (Burstrom et al., 2012). These studies suggest that coping is multi-layered and multidimensional and multiple mechanisms are employed in coping. These mechanisms may lead to appropriate adjustment or not. They also show that different factors influence the process of coping and the choice of the mechanism employed. These studies were all done in the western context and, therefore, there is a need to understand coping from a purely African perspective.

End of life issues

Literature about End of Life (EoL) issues reveals that discussions about this subject rarely take place between patients and health professionals. Reasons for this includes patients not being ready to receive the information and health professionals reluctance to provide the information, as illustrated in the following studies. Boyd et al.'s study (2004) showed that patients did not have EoL discussions with Health professionals and were not aware of how imminent death was. Willems et al. (2004) in a qualitative longitudinal study of 31 HF patients found that only 18 participants were prepared to

talk about EOL issues. These authors described how patients thought of death infrequently except during exacerbations and did not expect to die soon. Those who felt they had defied death in previous exacerbations of their illness hoped to continue to do so. However, the experience of nearly dying in the past had prepared some for dying. Therefore, a common experience was that of vacillating between wishes of death, due to the dependency that illness had imposed on them and wishes to be alive as they would still be useful to their families. When patients were willing to discuss EOL issues in Willems et al.'s study (2004), two topics commonly came up namely: preparation for dying; and views on medical decisions concerning end of life. Patients wanted information on what to expect, they wanted life-prolonging treatment to be discontinued or withheld when appropriate but rejected euthanasia and hoped for a quick death that is not associated with prolonged suffering. Some patients' views of euthanasia evolved through their illness from a complete rejection of euthanasia to its consideration if there was much suffering (Willems et al., 2004). In a review by Barclay et al. (2011) patients preferred information on prognosis to be given at times of hospitalisation, but they did not want information during the times when they were stable. Health professionals did not often discuss EoL issues because they had difficulties prognosticating HF and sometimes did not recognise the EoL, they also admitted to having communication problems and feared to cause undue anxiety (Barclay et al., 2011).

2.1.11 Experience of health services

Research evidence shows that HF patients' experiences of health services did not meet their expectations. In Murray et, al.'s study (2002) participants reported that their care was often professionally led and not a partnership and was based on a medical model that is treatment focused. Although some participants liked this prevailing arrangement, those who did not like it feared to challenge the health professionals for fear of sanctions against them. Good communication skills among health professionals, continuity of care and an approach that took into account their emotions were much appreciated. Negative hospital experiences included poorly coordinated care, lack of privacy and dignity and a lack of personalised care (Murray et al., 2002). This study also interviewed the health professionals on their views about their care and found that health professionals recognised the gaps in care and suggested a range of models of care that could meet the patients' needs including

home visits, better coordination between hospital and community, improved communication and involving specialist palliative care services (Murray et al., 2002. Boyd et al., 2004). Factors identified in the literature as hindering a therapeutic relationship and affecting patients' confidence in health professionals included; poor communication, poor coordination of services, patients feeling that they were perceived as pretenders or time-wasters, inadequate skills from HPs, lack of time for patients, participants feeling that they were not heard and their notes not being reviewed, difficulty accessing services and lack of continuity of care leading to change in medications. (Ryan and Farrelly, 2009. Welstand, Carson and Rutherford, 2009. Gallacher et al., 2011). Positive experiences with HPs resulted from a trusting relationship with the health care provider and if they provided guidance in making decisions in times of instability (Welstand, Carson and Rutherfore, 2009). A review by Jeon et al. (2010) also revealed that there were inefficient referral systems between physicians and specialists, and physicians were hard to contact, rushed and uninformative and inattentive to patients' needs. Examples participants gave of good care in this review included: giving consistent advice; showing care; being knowledgeable; and giving practical guides for self- care. Good quality care led to confidence, rapport with the care providers and patients feeling secure. Poor practice according to patients included: not involving patients in care and decision making; not giving sufficient information; having an insensitive approach creating unnecessary fears; not attending to immediate needs; and, ignoring patients (Jeon et al., 2010). Patients expressed the need for regular clinic visits to someone who knew them and to have a HF contact to seek advice and support from on the telephone as a means of increasing security (Liljeroos et al., 2014). In another study participants valued home visits and telephone access to health professionals. Distress was caused by long waiting times and poor communication. In another study, patients felt upset at 'having to fight for services' they felt they should receive (Ross and Austin, 2015).

2.1.12 Health professionals' perceptions of patients' palliative care needs in heart failure

Most of the literature on the health professionals' perceptions of palliative care in HF revealed that they acknowledged the need for palliative care for advanced HF patients. However, in most cases palliative care was not integrated into the care of these patients. Therefore most literature highlighted barriers to the provision of

palliative care in HF patients and some literature identified the specific needs of these patients as well as ways care can be improved from the health professionals' viewpoint. These findings are discussed in detail below.

Barriers to the provision of palliative care in heart failure from the health professionals' perspective

Hanratty et al. (2002) undertook focus group interviews of general practitioners, palliative care specialists, cardiologists and geriatricians and identified health system issues such as poor coordination of services and lack of continuity (as patients often had to see a different cardiologist when they were reviewed) and lack of palliative care services for HF patients in the community as barriers to the provision of palliative care in this condition. Other barriers that were related to the health professionals included uncertainty of the prognosis of HF which led to uncertainty on when to start palliative care and when to communicate the bad news. Non-palliative care doctors were concerned that breaking bad news too early may make patients lose faith in them or patients may give up the fight for life. There was also concern about the demands breaking bad news could have on the health professionals in terms of supporting the patients psychologically (Hanratty et al., 2002). Barriers related to the communication of bad news were echoed in the findings of McIlfatrick (2007) and Hupcey, Penrod and Fogg (2009). Selman et al's interviews (2007) with six palliative care clinicians and six cardiology clinicians revealed that end-of-life care for HF patients was not provided because of the following: the unpredictability of the prognosis of HF; the public perception of HF as a benign condition and the reluctance of health professionals to challenge this as a way of protecting the patients; a lack of skills and competency in communicating and discussing end-of-life issues as well as dealing with patients reactions and concentrating on the curative aspects of HF. Murray et al.'s findings (2002) on the barriers to palliative care provision for HF patients from the health professionals' perspective resonated with those of the above studies and they included protecting patients by not giving them bad news, lack of acknowledgement that HF was a terminal condition, discomfort in initiating conversations on death and dying and a lack of enough resources for these patients to facilitate the provision of care.

In another qualitative study to understand nurses' perceptions of factors influencing the provision of palliative care for HF patients, it was found that there were several barriers hindering the delivery of care. These included: the inability to identify end-stage HF and its complications; poor knowledge of the philosophy of palliative care; not having a relationship with the patient which affected communication; health professionals not being comfortable about their own dying; poor communication in the interdisciplinary team; a lack of resources to meet needs; and no continuity of care (Wotton, Borbasi and Redden, 2005). Rogers also found that health professional related barriers such as fear of uncovering psychosocial issues which they were not competent to handle, lack of community services, difficulty in accessing social services, lack of acknowledgement of palliative care by cardiologists, lack of expertise in prognostication and when to start palliative care hindered palliative care provision. A unique barrier identified in this study was the lack of time for carrying out palliative care assessments. It was also difficult for the health professionals to switch roles from curing to care, and for those who did, it was difficult to refer patients to palliative care services for fear of losing skill in management of those who are dying (Rogers et al., 2002). The health professionals in Boyd et al.'s study (2004) identified the following as barriers to the provision of palliative care to include lack of individualised patient information and finding the right language to communicate the diagnosis and prognosis without raising undue anxiety and without being misunderstood by the patient when they used the word HF. In the qualitative study by Brannstrom, Forssell and Pettersson (2011) barriers to the provision of palliative care included lack of time, difficulty in determining when to initiate palliative care, and fear of destroying hope which hindered communication on end-of-life issues. Physicians in this study struggled with decision-making on the use of implantable Cardioverter Defibrillators and when and when not to perform heart/lung resuscitation (Brannstrom, Forssell and Pettersson, 2011).

Health professionals' perceptions of patients' needs and the services required for better care

According to the health professionals in Hanratty et al.'s study (2002), unmet patient needs included: a lack of home-based care, lack of social services, unplanned care for the dying, a non-holistic approach in the management of these patients, poor teamwork among specialties and a lack of funding for care of HF patients.

Rogers et al. (2002) identified the need for practical help, listening to patients and assessment and management of physical symptoms that were not directly related to the HF, which were often forgotten. Brannstrom, Forssell and Pettersson (2011) found that physicians recognised the need for devoting time to patients and giving them a chance to express their distress, but there was little time to hold conversations about existential issues. Continuity of care, palliative care referrals and follow-up of patients were identified as important requirements to improve future care but there was uncertainty regarding who should take over the primary care of the HF patients between the different specialists of physicians as some doubted if appropriate care would be given by non-cardiologists (Brannstrom, Forssell and Pettersson, 2011). From interviews with patients, their carers, and health professionals it was evident that services for HF patients should not be based on ones' estimation of prognosis because of prognostic uncertainty but there is need for an integrated approach to care planning that takes into consideration the trajectory of this illness. Regular review and continuous review of goals of care and care given as patients move through phases of their illness was recommended for community-based programmes (Boyd et al., 2009).

Suggested models of care for improved care

Several approaches and models have been suggested by health professionals in the provision of palliative care for patients with HF with general agreement on joint care in most cases, but no clear agreement on who should take the lead role. In Hanratty et al's study (2002), general practitioners and geriatricians felt that they were more suited to provide palliative care for the dying HF patients and felt palliative care doctors would not be able to manage these patients as competently as themselves. They agreed that different models of care may be needed in the community and they suggested a model with a key worker, a member of the team to coordinate and oversee all activities (Hanratty et al., 2002). In the study done by Selman et al. (2007) the health professionals felt that care for patients with HF could be improved by joint care between cardiologists and palliative care specialists and mutual education with each specialty benefiting from the knowledge of the other, having referral criteria and care pathways to facilitate joint working and better communication with the patients and within the interdisciplinary team. The importance of joint care for better outcomes was also highlighted by Wotton, Borbasi and Redden (2005) with a proposition that cardiologists would take the lead role with palliative care specialists

as consultants. Specialist HF palliative care nurses suggested earlier referrals of patients in NYHA class 111, provision of intravenous diuretics in the community, regular multidisciplinary team meetings, running joint clinics, support groups for patients and families, access to physiotherapy, holistic assessment by all health professionals, shift from disease to person-centered approach, role modeling, consultant palliative care support, more integration with specialist palliative care specialists, and administrative support as means of improving care for HF patients (Rogers et al., 2002). Boyd et al's findings (2004) from General Practitioners in Scotland propose a range of approaches and models to meet patients' needs including having home visits, better coordination of services between home and hospital, better communication among health care providers, having a heart failure nurse specialist and extending the role of specialist palliative care services.

Summary

The literature on the experience of patients with HF revealed that there was a large and broad body of literature on this subject from high-income countries covering the following areas: the illness trajectory; physical symptoms and co-morbidities; life disruptions; dependence; social isolation; effect of illness on relationships; financial needs; psychological symptoms; living with loss; spiritual experiences and needs; information needs; self-care; experience of the treatment of HF; QoL; coping with HF; dying of HF; patients' views and experiences of healthcare services; health professionals views of HF care; and barriers to the provision of PC for patients with HF. However, there was a dearth of information on the subject from Africa. The few studies from Africa on the HF experience employed quantitative methods and they focused on physical symptoms, QoL, psychological symptoms and adherence to treatment. The patient's voice was not evident in these studies. Therefore the current study adds value by providing insights into patients' multidimensional experiences and needs over their illness course and what constitutes quality care by using the patients' voices (in qualitative interviews) in an African context where the cultural, economic and social factors differ from those in high-income countries.

CHAPTER THREE

3.0 Methodology

In this chapter, the research question and study aims are outlined and the chosen research approach and study design are described. The theoretical framework and methodology underpinning the design of this study are also explained. Justification for the choices made is provided and the details on participant recruitment and data collection are documented. The chapter also discusses how matters of ensuring quality and ethical conduct of research were addressed.

3.1 Research Question

What are the physical, psychological, social, spiritual, information and health care needs and experiences of Ugandan patients with advanced HF, how do they change over the course of their illness and how do services meet these needs?

Sub–research questions

i) What are the physical, psychological, social, spiritual, information and health care experiences and needs of Ugandan patients with advanced HF?

ii) How do the multidimensional needs and experiences of Ugandan patients with HF change over the course of their illness through diagnosis, treatment and dying?

iii) How do the available services and service providers for HF meet the need and what services are needed to improve care for HF patients?

3.2 Aims of the research

i) To understand the multidimensional experiences, needs, and use of services of patients with HF along their disease trajectory.

ii) To understand health care professionals' perceptions of patients' needs, the care required and the availability of services for patients with advanced HF.

3.3 Objectives of the research

1. To map patients' experience of being diagnosed with, treated for, living and dying of HF in Uganda.

2. To map the pattern of patients' needs and concerns over the course of their illness and the factors influencing the changes.

3. To map services available to patients and to consider how they match with need.
4. To describe health professionals' understandings of patient needs, care required and service availability.
5. To capture from both patients and professionals perspectives what would constitute better care and how this can be achieved.

3.4 Research design

3.4.1 Introduction

In planning and designing this study, approaches and methods that would answer the research questions best, as well as be coherent with the research philosophy that was adopted were considered. Ethical, feasibility, validity and reliability issues influenced the development of the study design.
A longitudinal study, using serial qualitative interviews followed with a short questionnaire, (the African Palliative Care Association African Palliative care Outcome Scale - APCA African POS) was conducted to meet the research objectives.

3.4.2 A qualitative approach

Qualitative research has a major part to play in the field of Medicine (Giacomini and Cook, 2000. Malterud, 2001. Shuval et al., 2011) and seeks to answer questions about the 'what', 'how' or 'why' of a phenomenon (Green and Thorogood, 2009).

Why qualitative research?

As elucidated by Nettleton, '*The chronic illness experience is a complex phenomenon and responses to illness are not simply determined by either the nature of biophysical symptoms or individual motivations but rather are shaped and influenced by the social, cultural and ideological context of a person's biography. Thus, illness is a personal and a public phenomenon* (Nettleton, 1995, p69). Thus, it is appropriate to use sociological methods to explore patients' experiences in this study. The qualitative research approach has been tested and tried in several studies in other settings, which have explored people's experiences with chronic life-limiting illness and has enabled detailed analysis of the holistic experience helping to develop a conceptual and theoretical understanding of living with the disease and presenting

views on ways to improve services and unmet needs. In order to develop interventions that will be effective, there is need to understand the underlying causes, processes and customs influencing behaviour and their context. A qualitative research approach illuminates these (Barbour, 2007) and is important in the development of interventions that are specific to cultures and context and are therefore more likely to be acceptable to the users. The qualitative approach facilitates exploration of the social mechanisms which link variables such as culture and adaptation to illness, and how the macro (such as their response to illness) is translated into the micro (patient's understandings) because it generates in-depth information (Barbour, 2007). Thus, a qualitative approach is essential in eliciting patients' understandings of their illness and their experience with chronic illness which may affect their health seeking and health sustaining behaviour. Additionally, qualitative research crosscuts disciplines and emergent themes are not dominated by any one discipline (Lincoln and Denzin, 2003).This is important especially in research in palliative care where a holistic understanding is crucial to improving care.

At a policy level, qualitative research has the ability to give policy makers theories of social action grounded in the experiences of both patients and clinicians (Lincoln and Denzin, 2003),which can help inform service development. This is important with the current emphasis on patient involvement in planning their care.
Although quantitative approaches can provide useful numeric information with respect to symptom burden and outcome measurement, they do not explore in detail the underlying social mechanisms and cannot explore concepts such as people's understanding of their illness and their illness experience, which are both subjective. Therefore, quantitative methods were found not to be suitable for eliciting the holistic illness experience.

3.4.3 Theoretical Perspective

The purpose of this study was to understand the changing needs, concerns and experiences, service provision and perceptions of quality of care for patients with advanced HF. This was done by drawing on insights given by those who had the condition and health care professionals involved in the care of this condition.
In developing the research methodology, I had to reflect on my ontological and epistemological positions as these would influence my approach to research and how

I would interpret the outcomes of the research. In exploring the literature, to identify my ontological and epistemological positions and the theoretical perspective which would inform this study, my beliefs resonated with Creswell (2007) that embracing a particular stance does not oblige the researcher to always frame their research in that perspective.

My ontological position for this study takes a middle position between the relativism and realism view. Realism argues that there is an external reality that exists independent of people's beliefs or understandings about it, whereas relativism asserts that reality is only known through the human mind and through socially constructed meanings (Snape and Spencer, 2003). I believe that physical realities exist but I also would argue that our previous experience, knowledge and our contexts influence our understanding and interpretation of what we encounter. In reference to this, my ideas resonate with Andrews' illustration (2012) using the example of disease and illness where he argues that disease is a reality that exists but naming of the disease and what defines disease may be socially constructed. Therefore, I take the position of 'subtle realism' proposed by Hammersley that social phenomena exist independent of people's representations of them but are only accessible through these representations. (Snape and Spencer, 2003).

For this research, an interpretive theoretical perspective based on constructivism was employed. An interpretivist approach has the advantage of eliciting a rich and detailed theory related to individual perceptions of social issues (Arksey and Knight, 1999). Constructivism asserts that knowledge and what we know of the world and ourselves (truth and meaning) is constructed as a result of interaction with the realities of the world (Braun and Clarke, 2013). This approach was chosen because constructivism recognises that people develop subjective meanings of their experiences which are multiple and these are influenced by their social, cultural and historical context, which I believe is the case in the illness experience, the subject of this research (Creswell, 2007. Braun and Clarke, 2013). Constructivism has the propensity to getting an in-depth perspective of patients' experiences as it considers different perspectives. The constructivist position is also important to capture the participants views and allow them to be involved in the decision-making process and is an easy way to understand a group because individual knowledge is usually ascertained from

one's daily contacts. The constructivist epistemological stance also recognises that the researcher's background shapes their interpretation of what they find. In constructivism '*the researcher interprets the meanings others have about the world'*. (Creswell, 2003, p9).

The constructivist approach therefore meets the purposes of this research, which is to understand the multidimensional experiences and needs of patients with HF in the Ugandan context. Although most of the research was based on the constructivist theoretical perspective, I also drew on the notions of Pragmatism. '*Pragmatism does not commit to any one system of philosophy but focuses on the problem being studied and the questions asked about this problem and individual researchers have the liberty to choose methods techniques and procedures of research that best meet their needs and purposes*.' (Creswell, 2012 p,28) Therefore, pragmatists look to many approaches to collecting and analysing data (Creswell, 2012). I employed the notions of pragmatism by using more than one data collection method and using multiple perspectives in order to meet the needs of this study. Methodological triangulation is not unusual in qualitative research and has the advantage of giving holistic insights into an experience (Denzin and Lincoln, 2008).

3.4.4 Methodology

The choice of the methodology was informed by the theoretical perspective described above (Crotty, 1998). Some of the principles of grounded theory methodology were employed because this methodology can generate analytical interpretations of the data which fit well into the constructivist theoretical perspective. In grounded theory, the report on personal accounts is not a direct representation but a second-order construct but still enables emphasis on personal experiences that can inform practice.

Grounded theory has given very useful insights in similar studies on the illness experience, since its discovery in the groundbreaking research of Glaser and Strauss (1967) that led to the conceptualisation of death and dying in hospitals. Also, the methodology enabled conceptualisation of the chronic illness experience in the work done by Charmaz (1995). Grounded theory methodology is also widely known and accepted within the field of medicine through publications in peer-reviewed journals.

Grounded theory is a methodology where data are systematically gathered and analysed to construct theories that are grounded in the data (Glaser and Strauss, 1967). In grounded theory, the researcher generates a general explanation (a theory) of a process, action, or interaction molded by the views of the participants (Strauss and Corbin, 1997. Creswell, 2007). Grounded theory provides a rigorous, systematic approach to the inductive generation and analysis of data, using constant comparative analysis and theoretical sampling (Glaser and Strauss, 1967. Charmaz,1995). In the constant comparative analysis, interpretation of data moves forward through comparing intrapersonal and interpersonal views, experiences, situations and actions as well as comparing data for emerging categories (Charmaz, 1995. Green and Thorogood, 2009). Grounded theory encourages intense coding to identify emerging concepts and categorising of these concepts under the different phenomena to which they relate. In this way the analysis is less descriptive and more analytical (Green and Thorogood, 2009). It relies on theoretical sampling whereby sampling of participants is dictated by the emerging data and data analysis: this is guided by the desire to refine emerging concepts and theory. The initial generation of data is from a purposively selected sample and written records or 'memos' are kept throughout the whole process of the research to perfect one's thinking of the data. Attention is given to deviant cases when developing theoretical insights (Green and Thorogood, 2009). For this research, the principles and techniques of grounded theory that were employed included purposive sampling, the intense coding, categorising of concepts analyzing for deviant cases and the constant comparative method in analysis.

I drew heavily on Charmaz's approach (2006) to grounded theory for this study. Charmaz (2006) proposed the use of grounded theory to 'develop social constructivist analyses' also termed as the 'constructivist grounded theory'. This approach to grounded theory fits well with the subtle realism epistemological stance that was adopted for this research. I concur with Charmaz (2006) that '*ill people's constructions reflect their understandings of their experiences and the diverse situations in which they have them and there are multiple social realities which results from social interactions, negotiations and power' (* Charmaz, 2006, p1161) and that *'data do not provide a window on reality, rather, the discovered reality arises from the interactive process and its temporal, cultural and structural contexts.*' (Charmaz, 2006, p1164) Although Glaser (1978) argues that grounded theory is

ontologically and epistemologically neutral, many have criticized this premise as naïve and non-committal (Bryant, 2009). Holton, a proponent of the classical grounded theory approach improves this position by arguing that classic grounded theory can adopt any epistemological perspective appropriate to the data and the ontological stance of the researcher. (Holton, 2009,p 269, Breckenridge et al., 2012)

One of the essential principles of the constructivist grounded theory approach is keeping the participants voice and meaning in the final research outcome (Breckenridge et al., 2012). This is one of the reasons I drew heavily on this approach of grounded theory because it resonates well with the principles of palliative care that is giving voice to the participant that will benefit the participants directly, in addition to generating data that can be used at policy level. Munhall (1988) argues that keeping the participants voice in the final research outcome meets the researcher's obligation to '*describe the experiences of the participants in the most accurate way possible*' (Munhall, 1988, p153). However Glaser (1978) contends that grounded theory was not designed for giving voice to the patients but to identify and explain conceptually an ongoing behaviour that seeks to resolve an important concern of the participants (Breckenridge et al., 2012). In my opinion by trying to get one major concern or the basic social process there is a risk in this process to force information to fit in one overarching category and eliminating important concerns which do not fit into that category. I also believe in the other tenet of constructivist grounded theory that the data generation and analysis is a co-construction of the researcher and the participants and the interpretations are from both participants and the researcher, unlike in the classic grounded theory where it is emphasised that the researcher is objective and '*data exist in the world, the researcher finds them and discovers theory from them but are not defined by actors and analysts'* (Charmaz, 1995, p131). I argue that the researcher has a big role in what data and concepts will be generated and even if measures may be taken to reduce this or to be objective there is tacit or taken for granted assumption researchers may not be aware of, and therefore it is difficult to identify the objective truth. Also a researcher's interests, perspective and values will influence the questions asked and how data is analysed.

In the classic grounded theory Glaser and Strauss (1967) contend that grounded theory is purely inductive and that one should go into the field to collect data

uncontaminated with literature from other studies which they refer to as going in with a 'tabula rasa' so as not to interfere with the data analysis. They instead propose that the literature review should be done after data generation at the stage of analysis (Glaser and Strauss, 1967). In my research, I chose to review the literature before, as a means of identifying the gaps and providing a rationale for the study as proposed by Hutchinson, Sally and Wilson (2001). I also agree with Strauss in his later article with Corbin (where his position on when to do literature review changes from the original one with Glaser) for an early literature review as a way of stimulating theoretical sensitivity and stimulating questions (Strauss and Corbin, 1997). An earlier literature review can also help in identifying methodological pitfalls from previous studies (McGhee, Marland and Atkinson, 2007). In proposing going with an empty slate Glaser and Strauss (1967) assume that any researcher would have significant knowledge in the professional and disciplinary literature to enable them to think conceptually (Hallberg and Hallberg, 2010), but this is to assume that all researchers will have a background in the social sciences and this may prohibit researchers, such as myself, with other backgrounds. The literature review was also used to gain conceptual clarity as to be able to formulate a research question (Cutcliffe, 2001).

3.4.5 Methods of data generation

Choosing a research method

Several methods were evaluated for their suitability in meeting my research objectives as well as their ability to fit into my theoretical perspective. As explained above, I thought a qualitative approach was the best means of understanding the illness experience. I therefore went on to explore the different qualitative methods that would generate data that would meet my research objectives and would be practical and ethical. I concluded that in-depth interviews would be the best method to generate the required data to meet the study objectives.

Why qualitative interviews?

The choice of this method was guided by the nature of information I wanted to get, such as locating events chronologically in the patients' experiences including their multidimensional changing needs. This can be best obtained from interviewing. Also, an interview is a legitimate way to generate data on this research area by interacting

with research participants, talking and listening to them to gain a detailed access to their accounts (Mason, 1996). The intimacy of one-to-one or paired interviews enables discussion of sensitive issues around diagnosis and prognosis. Talking is a practice familiar to participants and may be less draining than lengthy questionnaires or complicated instruments, which is important for this ill population. Furthermore, the African tradition is an oral tradition and therefore, talking is a method of generating rich information. In-depth interviews with open-ended questions, using an interview guide, allow the interviewee to speak freely of matters most important to them which is crucial for getting in-depth information. The interview guide helps the interviewer to clarify presupposed areas gathered from the review of the literature. Interviews also fit well with the constructivist framework as they enable interaction of the researcher with the participant encouraging the active creation of meaning. Qualitative interviews have been criticised for giving information on only what people say and not what they do and Green and Thorogood (2009) challenge this criticism and contend that '*qualitative data is valid as long as the interview is treated as a contextual account and not a proxy representation of some other reality*' (p102).

Why other methods were not employed

Focus group discussions were ruled out for generating data from patients because of practical and ethical reasons. I thought that it would not be practical to convene the same focus groups over time since this was a longitudinal study. Additionally I envisaged that patients would be at different stages of their illness and bringing them together may lead to acquiring unwelcome or disturbing insights from their peers (Barbour, 2007). I rejected the use of qualitative surveys because they are not flexible in nature and can lead to limited responses and one has not got the opportunity to probe (Braun and Clarke, 2013). Use of diaries can meet the need of having rich longitudinal data on patients' experiences but it was overruled in this study because of the anticipated low literacy rates among the study population and a culture which is more oral and not used to documentation. Observational methods were not chosen because personal accounts of patients' experiences and how they made sense of their experience was required from this study and a purely observational method would not generate this information.

A multi-perspective approach

Patients, health professionals and sometimes 'patient-family carer' dyads perspectives were elicited in order to get a comprehensive view of the illness experience and the patients' needs, and for depth and richness as has been found in other studies (Thurmond, 2001). This complementary approach was also used to enable understanding of the dynamics between patients and professional carers. Understanding needs from different perspectives was thought to be important in formulating recommendations acceptable to patients and professional carers by assimilating their views (Pinnock et al., 2011).

Qualitative longitudinal interviewing

An increasing number of studies in health are using longitudinal interviews to look at people's experience of illness over time. Longitudinal interviews are used to study complex and evolving processes (Molloy, Woodfield and Bacon, 2002. Eborall et al., 2007). Qualitative longitudinal interviews are able to illuminate important micro social changes and processes such as the way people negotiate the changes that occur in their lives at the time of personal life transition (Holland, Thomson and Henderson, 2006). This is important in this study that has one of its aims as mapping changing needs of patients in their disease trajectory. If change is not dramatic, it may take time for its consequences to unfold or be visible in a cross-sectional study; however, with a longitudinal study this may be more possible to detect (Farrall, 2006). Qualitative longitudinal interviews also make it possible to investigate how peoples' everyday attitudes and actions are embedded in patterns of social cultural change (Holland, Thomson and Henderson, 2006). Another advantage of qualitative longitudinal research is that there is time to develop a relationship between the researcher and the participants (Murray et al., 2009) which enables discussion of sensitive topics.
All these issues were considered essential for this study. Through qualitative longitudinal interviews, one can identify changes in what patients want, the most appropriate way to carry out interventions and which outcomes are important to patients at what time in their disease trajectory. This was considered important for making future recommendations from the study. For this study, data generation was conducted over a period of 6 months from the time of the first interview.

This time frame was chosen based on the literature that revealed the short trajectories for patients with advanced HF - 20% mortality at six months for all HF (Damasceno et al., 2012). I aimed at three interviews for each patient, keeping in mind the definition of a longitudinal study as one where subjects are assessed at a minimum of two points in their lives spaced over months (Schulsinger, Mednick and Knop, 2012). For those patients who died after just the one interview, I planned to get the second interview from their bereaved carers.

3.4.6 Data collection

3.4.6.1 Study sites

The study was conducted on the general cardiology ward in Mulago Hospital and the patients' homes depending on their location at the time the interview had been scheduled. Mulago Hospital is the main national referral and teaching hospital in Kampala, Uganda and patients with HF are admitted to two different wards: a) the cardiology unit in the Department of Medicine which is a general ward; and b) the Uganda Heart Institute which is a private semi-autonomous unit within this hospital. The general cardiology unit was chosen because the social and cultural circumstances of patients admitted to this ward are thought to be similar to those of most HF patients in Uganda. The general cardiology unit in Mulago is a 50-bedded unit located within a bigger ward. The bigger ward also accommodates the pulmonology and renal diseases units. The cardiology unit admits about 2,000 patients with heart disease per year and 350 (17%) of these patients have HF. I planned to do most or all first interviews in the hospital where all patients were seen first and then the subsequent (second and third) interviews at home or in hospital depending on where the patient was at the scheduled time of the interview as established by a phone call.

3.4.6.2 Sampling

Purposive sampling, which is the characteristic approach of sampling in qualitative research, was employed for this study. Purposive sampling was used to gain insight and in-depth understanding of the experience of HF as participants were chosen on the basis that they would give information rich data (Braun and Clarke, 2013). The type of purposive sampling used in this study was criterion sampling. Patton (1990) describes criterion purposive sampling as one in which a decision is made prior to the beginning of a study to sample subjects according to preconceived criteria of certain

importance. Participants were therefore purposively sampled to represent the local demography of the condition that is strongly associated with the disease causes. In the review of the database of HF patients performed at the start of this study, HF clustered around two different age groups, the 20-40 years age group and the 50-80 years age group. These groups also had different causes of HF, therefore sampling aimed at including patients from each of these age groups as it was anticipated that their experiences could be different. I anticipated that recruiting 16-20 participants would give a broad understanding of the research area and considered this number as practical in the time available. Health professionals were purposively sampled based on whether they were directly involved in the management of patients with HF. Diversity of health professionals was ensured for a broad range of views because the different health professionals have different roles in the management of HF patients and it was therefore believed that they would provide multifaceted views on the needs of these patients and how care could be improved.

Eligibility criteria

Inclusion criteria for patients:

- Patients admitted in Mulago Hospital with advanced HF. The operational definition of advanced HF was adapted from the criteria used by Metra et al. (2007) and for this study advanced HF was defined as the presence of any four of the following five criteria:

  1) severe symptoms of HF with dyspnoea and or fatigue at rest or with minimal exertion (NYHA functional class III or IV).

  2) episodes of fluid retention.

  3) objective evidence of severe cardiac dysfunction shown by a low Left ventricular ejection fraction<30%.

  4) severe impairment of functional capacity.

  5) history of 1 or more episodes of hospitalisation in the past six months.(Metra 2007, p, 685)
- Patients who were 18 years old and above.
- Patients who consented to participate in the study.

- Patients whose home was within a catchment area of 30 kilometres from Mulago Hospital and whose ancestral home was not more than 80 kilometres from Kampala.

Inclusion criteria for family carers:

- Family carers of patients who requested that their carers should participate in the interview.
- Family carers of those patients who died during the study period (for bereavement interviews).

Inclusion criteria for health professionals:

- Health professionals directly involved in the care of patients with HF.

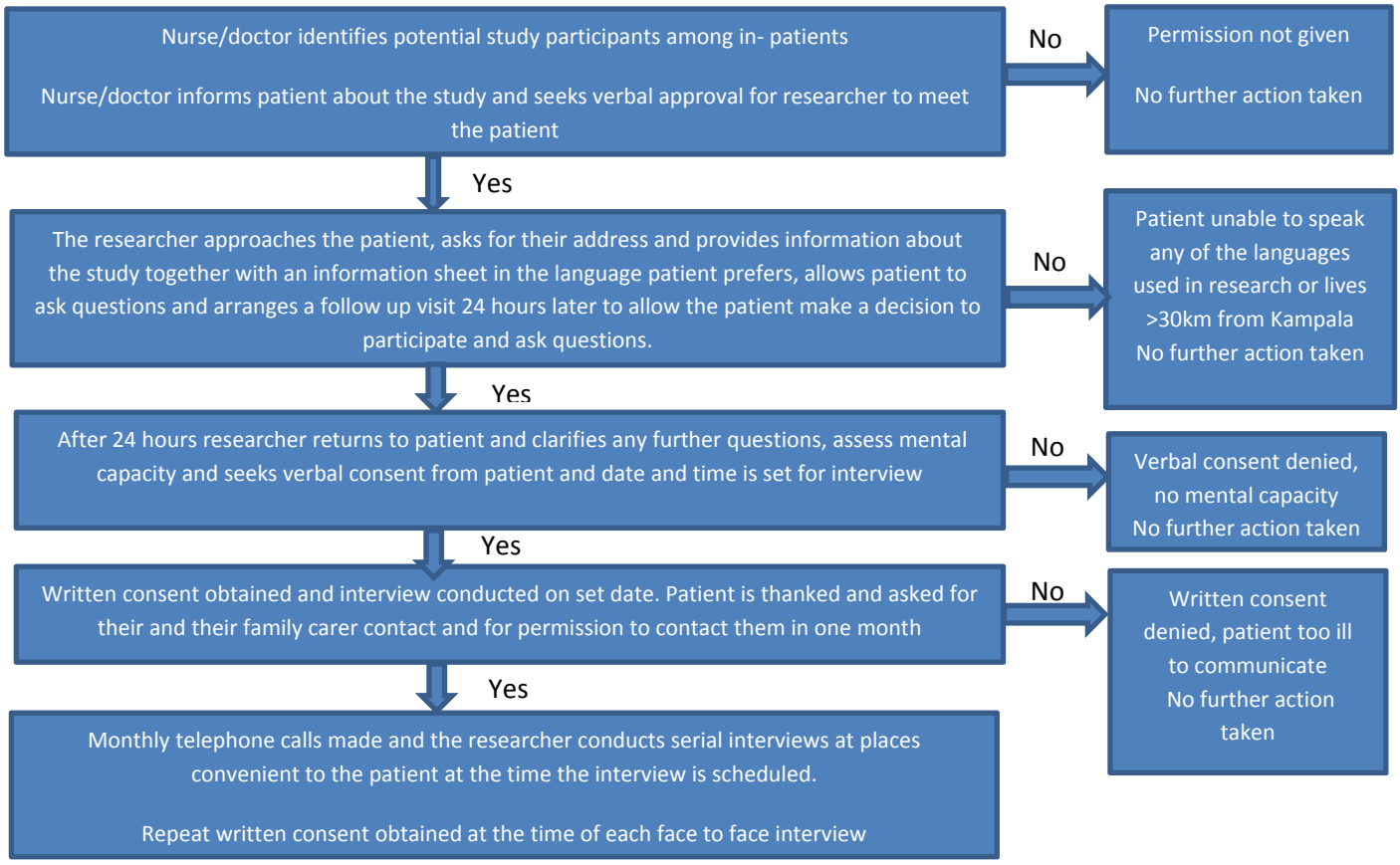
Exclusion criteria for patients

- Patients with diminished cognitive capacity such that they could not make an informed decision to take part in the study.
- Patients considered too ill, and with profound communication deficit, as the study was anticipated to involve long conversations.
- Patients who could not speak Luganda or English, which are the languages spoken by the researcher.

3.4.6.3 Recruitment of study participants

Patients were recruited in the study period based on the recruitment strategy represented in the flow chart in figure 2 below.

Figure 2: Recruitment plan flow chart



After obtaining ethical approval from the University of Edinburgh, Mulago Hospital and the Uganda National Council of Science and Technology (Reference numbers D/GC/178; MREC 33, SS 3083 see Appendix seven), the doctors and nurses on the cardiology ward were informed about the study and asked for their approval to recruit from the wards. A Sampling Grid for identification of potential patients suitable for recruitment was made available on the ward, which described the features of advanced HF in the operational definition used. I requested that staff alert me of patients with a diagnosis of HF along with the features of advanced HF as described in the operational definition and sampling grid. Information that was given to me about patients at this stage was anonymous. For those patients who were identified as fitting the criteria, I asked the staff nurse/doctor to inform them about the study and request permission for me to approach the patient. If, and when, permission was granted I met with the patient and provided details of the study including risks and benefits alongside a patient information sheet in the language they could read and I gave them the opportunity to ask any questions.

I then left the patient with the information sheet and arranged a follow-up visit 24 hours later to allow them to consider participation. On my return, if the patient agreed to be interviewed we set a time and place, which was usually a quiet place on the ward or at the patient's bedside. Mental capacity to provide consent was assessed as well as the patients' physical condition and ability to communicate. Written consent (signature or thumbprint) was obtained. After each interview, the patient was thanked and informed of the next steps. The patient's and their main family member phone contact were obtained (with their permission) and recorded at the end of the interview to enable subsequent interviews.

Interview calendar

The first interviews were planned to be conducted in the hospital, with the provision of doing the first interview at home if patients were discharged before they were well enough for an interview. The follow-up interviews were carried out in the patients' homes or on the hospital ward if they were re-hospitalised. The records system in Mulago Hospital is just being developed and by the time of the interview there was no system to provide an alert that a discharged patient had been readmitted. Therefore patients were followed up monthly by making phone calls in order to retain the relationship and to provide an alert if there was any change in health status (A previous study by Lewington et al. (2012) had shown that about 70% patients and carers had a mobile phone). The triggers for subsequent interviews were if the patients' change was significant enough to lead to deterioration in function or if they needed hospitalisation and if, from the telephone conversation, there was perceived distress in the other non-physical dimensions. For those patients where there was no change in multidimensional experiences perceived with the monthly phone calls, the next interview was conducted after 3 months and after this the same procedure for the final interview was followed as described above. The follow-up interviews were planned to be conducted up to a period of 6 months. This time interval was based on literature that suggests that survival in HF is about 50% at 1 year (Friedrich and Böhm 2007) and I anticipated that in our setting where HF patients present with advanced disease for care the 6 month survival may be similar to the one-year survival in settings where HF patients present early. Only patients who live within a 30km radius from Mulago Hospital were interviewed because of transport cost restrictions. In Uganda, people who live in urban areas have two homes, one in the

city and one in their ancestral home, in the countryside. The latter is the family home where people live with other members of the extended family. When they are very sick their families tend to take them back to their ancestral home because there may be more practical care available, but also because if they anticipate that they will die it is cheaper to transport them alive than when dead, and culturally it is important to be buried with your ancestors. I planned therefore that in the event that patients were taken to their ancestral homes before the subsequent interview was done that I would follow them up if their home areas were not more than 80 km from Kampala.

The interviews carried out at home were aimed at illuminating the context of their experiences and how needs change based on environment. Also, if patients were not comfortable in the hospital, this was envisaged as a freer environment in which they could express themselves. If the patients were too sick to talk on subsequent interviews, but wished to participate and requested that a carer contribute, then interviews with the patient and their family carers were carried out with the family carers as proxy sources of information to understand the prevailing situation. This was made clear in the information sheet and patients and family carers were asked to consent for this. In the event that the study patient died before the end of the study, a sympathy card/condolence message was sent to their family carer and this carer was contacted a month later and if agreeable to them, a follow-up visit was done and a bereavement interview arranged and conducted at a convenient time for the family carers.

3.4.6.4 Methods of data generation

For this study, the methods of data generation chosen were informed by the theoretical perspective and methodology.

Interviews

Patient interviews

In-depth patient interviews using a topic guide were used for data generation. All the interviews were carried out by the same researcher. They were recorded using a digital voice recorder after obtaining consent for this from the participants. Before the research it was anticipated that some interviews would be carried out in English and some in Luganda (the commonest language used in Kampala), however, all

patients preferred to speak in Luganda and, therefore, all interviews were conducted in Luganda. It had been anticipated that patients may request for their family carers to be involved in the interviews. When this happened, I ensured that the family carer was fully informed of the study and completed a consent form that their information about the patients' needs could be used in the study. Any family carer information included in the study was noted as such. The study did not collect information about family carers' individual needs.

Bereavement interviews

It was anticipated that some patients would die before the next scheduled interview and it was felt that the research would lack important information on their needs in the last few days at the time of dying. Therefore, bereavement interviews were planned to help understand what patients' needs and concerns are at the time when they are actively dying, how services meet these needs and what could be improved to make the dying experience better. This was aimed at meeting the study objectives 1-3 where I wanted to understand the experience of dying of HF and how services were provided at this time in one's disease trajectory to meet the prevailing need. This is key in the development of palliative care services that aim at improving the quality of death for the patients as well as the experience of the family at this time. Only those family carers who are 18 years and older were interviewed in the bereavement interviews.

Health professionals' interviews

Individual semi-structured interviews were carried out with the eight health professionals who are involved in the diagnosis, treatment and care of HF patients at the recruitment site. The interview guide focused on the generation of information on health professionals' perspectives on how patients come for care and on the process of the diagnosis, treatment and follow-up of these patients and their perceptions of the patients' needs and care. To get a diversity of views health professionals interviewed included those from a medical, nursing and social work background. For this group, a single cross-sectional interview was conducted, this was done after completing all the patients' interviews in order to get the health professionals' reactions to the patients' needs and their views on how best they could be met. Health professionals were not matched to patient interviews as in other previous studies, because within the health system in Uganda, patients do not have a particular doctor who follows them all the

time because of the high health professional to patients ratios, but patients are reviewed by whoever is available.

Interview guides for patients and health professionals

The semi-structured interview guides for both the patients and the health professionals were informed by and derived from, the study objectives and previous literature. The guide was used to flag up any anticipated areas (Barbour, 2007) and was not strictly adhered to but it enabled the interview to cover the areas most pertinent while allowing the patient to speak freely. Open-ended questions were used to encourage patients to speak freely and prompts were used to promote further talk and elaboration (Barbour, 2007). The patients topic guide was translated into Luganda, the common language that was used for the interviews and was piloted on two patients, one in the younger age group and the other from the older age group, and the transcripts from these interviews were sent to my supervisors for review to ensure that the interview guide was 'fit-for-purpose' and was able to support the generation of the information it was intended to.

Use of tools

The Africa Palliative Care Association African Palliative Outcome Scale (APCA African POS) and the POS-Symptom (POS-S) tools were used to collect quantitative data on the multidimensional experiences of patients. Both of these tools were adapted from the palliative care outcome scale (the POS) a tool that assesses multi-dimensional aspects rated on a Likert scale. The POS was developed in the UK for use in patients with advanced disease to measure essential outcomes in palliative care (Dix, 2012). The APCA African POS was adapted for use in the African setting – where the questions can be self-reported and recorded by the patient, or they may be self-reported by the patient but the responses recorded by staff due low literacy levels. The APCA African POS was used to enable interpretation of the research in a clinical context so that clinicians would embrace the research better as this tool is currently used in clinical care in Africa to ensure all patients needs are assessed and addressed and it enables identification areas for improvement (Dix, 2012. Defilippi and Downing, 2013). It has also been validated for use in the African setting and its use in clinical care is being encouraged throughout sub-Saharan Africa. The tool was also validated and has been used in research prior to this one in Africa, and was found to

take between five to seven minutes to administer (Harding et al., 2010. Defilippi and Downing, 2013). Therefore, it was thought that the administration time for the tool was short enough not to exhaust the patients after an extended interview. The POS-S is another development from the POS and it is a tool with ten items that addresses the common symptoms prioritised by people with advanced illness. It can be used alongside the other POS tools and it is recommended to be used if question 2 of the POS tools suggests that the patient has multiple problematic symptoms. It is also recommended for assessing symptoms in HF (Cicely Saunders Institute, 2012). This tool was used alongside the APCA African POS because HF patients have multiple symptoms and since the APCA African POS is adapted from the POS the two tools are compatible.

Field notes

Field notes were written during the recruitment and at each interview on the process, outstanding observations and the environment to give context to the interview. Field notes were also written on phone conversations and patient records. Reflections on personal, methodological and practical challenges as well as ethical issues and reflexivity issues were written in field notes. All patients consented to basic information being extracted from their medical records to be used for this study so as to provide more information on their clinical state. Data collected included age, cause of the disease, results of their tests such as echocardiogram results and information on co-morbidities and treatment given.

Attrition

Considerable attrition was anticipated in this longitudinal study because of the possible short survival and increasing debility and travel issues. The sample size of 16 to 20 was therefore chosen with an anticipated total of at least 37 patient interviews (at least16 during first stage interview, 12 during 2nd stage interviews 3 months later, and 9 during third stage interviews 6 months after the interviews commenced). I also planned to do some interviews earlier if from the monthly phone calls significant change in patients' physical function was detected and it was anticipated that their prognosis would be shorter than six months. Establishing rapport early with the patients and family was ensured in an effort to reduce attrition rates.

3.4.7 Rigour in the study

The validity, reliability and generalisability of qualitative research in the health field have been contested (Mays, Pope and Journal, 1996). This is partly because the definition of rigour used in quantitative research has been wrongly used for the definition of this concept in qualitative research (Mays, Pope and Journal, 1996). Some authors argue that these terms common in quantitative research are not compatible with qualitative work. Terms such as credibility, authenticity, transferability and confirmability have been suggested by Lincoln and Guba (1985) for qualitative research as the equivalent of internal validity, external validation, reliability and objectivity. Qualitative researchers strive for rigour in different ways. Measures to enhance rigour in qualitative research include having systematic and self-conscious research design, data collection, interpretation and communication (Mays, Pope and Journal, 1995). Mays, Pope and Journal (1995) also stress that researchers should describe their method of data generation and analysis so that another trained researcher can gather and analyse the same data in the same way and draw the same conclusions (Mays, Pope and Journal, 1996). These recommendations were adhered to in this study. According to Mason (1996), validity means you are identifying what you say you are. Generalisability involves the extent to which you can make a wide claim on the basis of your research and analysis. Reliability involves the accuracy of your research methods and techniques (Mason, 1996). Creswell (2012) describes eight strategies used in the validation of qualitative research including long contact with participants; triangulation; peer review of the research process; clarifying researcher bias; rich thick description; external audits; and negative case analysis. He recommends that at least two of these should be employed (Creswell, 2012). In-depth, one-to-one semi-structured interviews were considered well suited for obtaining validity in this study because they give detailed accounts of patients experiences, other means to ensure validity in this study included longitudinal interviews that ensured more engagement with participants, triangulation, peer review and clarifying researcher bias.

Qualitative researchers acknowledge that they influence the knowledge generated and, therefore, many argue that reliability in qualitative studies should be thought of as the '*trustworthiness or dependability'* of the methods of data collection and analysis (Braun and Clarke, 2013). Reliability in this study was ensured by complementary data collection and using multiple approaches to data generation as

well as having my supervisors review some of the scripts and agreeing on the codes and themes. Empirical or statistical generalisability was not an aim of this study, as for many other qualitative studies, but theoretical generalisation was, and I hoped to get it through the use of the above methodology. I also thought that theoretical generalisability would be obtained at the end of the study by comparing data obtained in this study with data with similar studies elsewhere. I was reflexive at every stage of the study about my epistemological orientations and background and how these were affecting the research.

3.4.8 Ethical issues

Approval to carry out the research was obtained from the University of Edinburgh ethics committee, the Mulago Hospital Ethics Committee and the Uganda National Council of Science and Technology (UNCST) (Reference numbers: MREC: 313, D/GC/178, SS 3083 Attached in Appendix seven).

The research was carried out based on standards of good clinical practice and based on the four principles of medical ethics. It was not known if this research would benefit the participants directly and therefore patients were informed of the possibility of no gain. Written consent was obtained from the patients and their family cares, if the family carers were to participate in the interviews, before the interviews were conducted and written consent was obtained again before the subsequent serial interviews were carried out. All transcripts and audio recordings were anonymised. A distress protocol was put in place in case the research caused any distress to the participants. (Details of the protocol can be found in Appendix seven)

Consent

Potential participants had all the information available to them about the study in which they were considering to take part so that they could make an informed decision. Participants were asked to give written consent at each interview and capacity for consent was assessed at each interview by the researcher by having a brief conversation with the patient and asking them to explain what they had understood from the information sheet. If the patient was able to demonstrate that they had understood the study aims, risks and benefits, and if in their family carer's opinion the patient was considered fit to consent, then they were asked to give written consent. If the patient wanted their family carer to participate in the interview, they

were also asked to give written consent. Written consent was also obtained from health professionals who participated in the study.

Ethics of research with people with progressive life-limiting illness

Many patients with progressive life-limiting illnesses qualify for a definition of 'vulnerable' because they are very ill. Therefore measures were put in place to ensure their welfare was not being violated. There has been some opposition in the literature to recruiting people into research studies who are at the end-of-their lives (de Raeve, 1994), but this opposition has been countered by the recognition that research is important for improving care, and most ethical challenges in research in this area are not unique to this population (Casarett and Larlawish, 2000). Having said this, research fatigue is a real issue, and care was taken to assess risks to the participants. However, research participation can be beneficial for vulnerable people (Murray et al., 2009). For this research, when patients were distressed during the interviews, a distress protocol was followed as follows; the interview was stopped and the researcher who has some skills in counselling gave the patient immediate support and assessed if they were able to carry on with the interview. If the patient was able to carry on, the interview was continued. However, if the researcher's assessment showed distress or if the patient who had been considered able to carry on continued to be distressed, with the patient's consent and the consent of their primary care team, they were referred to the hospital palliative care team which has a social worker and health professionals that are trained and experienced in counselling for psychological support. (Details in Appendix seven). It was anticipated that the participants may feel a sense of loss at the end of the research and therefore measures were put in place to ensure that they had continued care and support within the existing health system at the end of the research by linking them into their HF clinics. All patients had not been referred for palliative care and did not know their prognosis, as it is not common practice for health professionals to tell patients their prognosis, therefore caution was taken to avoid potentially distressing terms in the study documentation given to the patients as argued by previous authors (Fitzsimons and Strachan, 2012).

Ethics of research in the field.

There was a potential role conflict that could occur during the data collection given my background as a medical doctor and my new role of a researcher. Therefore, I did

not reveal my identity as a doctor because this would potentially influence the data generated. The exception was when the patient asked whether I was a doctor to which I would reveal my identity but also let them know that currently I was a research student. If the patients had any medical concerns that were not emergencies, they were referred on to those caring for them in the health system. However, in the event of a life-threatening emergency, and if there was no one else to help, my obligation as a doctor to help a patient would take precedence over my role as recommended by Morse (2007). I often sought the advice of my supervisors whenever any ethical issues arose and I was reflexive of my actions during the data collection process, especially on the effect of my role as a doctor and my previous knowledge and expectations and how these would influence the research process.

Researcher welfare

This research involved engaging with participants, and through the interviews getting involved in their lives at a difficult time in their biography. For most of the time this was a humbling experience that helped me reflect on my life and appreciate it, but it was also potentially a cause of distress to me as a researcher, particularly as the relationships with the participants became stronger with repeated interviews,visiting their homes and getting to know them and their families. Although it was important to keep professional, sometimes it was hard to just push away some feelings and sometimes there were moral and ethical dilemmas that caused me distress. Regular debriefing sessions were therefore held with my local supervisor who is a palliative care specialist trained in providing psychological support. Keeping a journal also helped in releasing any distressing issues. The research also involved going to the field alone sometimes to areas far away from my home and place of work, which was a safety risk and therefore measures were put in place to ensure my safety whilst in the field.

3.4.9 Data management

Interviews were digital recorded and were downloaded to a secure password protected personal computer as soon as possible after the interview. The researcher re-listened to all interviews again immediately after the interview and wrote memos of first impressions of the data and the emerging themes to inform further interviews. Following this, the recordings in Luganda, were translated into English and

transcribed by the researcher and an assistant who is an administrative assistant from the palliative care unit in this hospital, both of whom are fluent in both Luganda and English. A translator fluent in the local language cross checked a sample of the translations to ensure the accuracy of the translated transcripts. Translation was aimed at conveying the meaning of what was said ('conceptual equivalence') and not always a literal translation, as translating literally may result in incomprehensible or misleading transcripts because' not all concepts are universal and not everything is translatable' (Birbili 2000, p3). It was also possible that translation did not give the exact equivalent or may result in loss of depth because of lack of 'lexical equivalence' but since qualitative research aims obtaining the meaning in a phenomenon conceptual equivalence was considered appropriate. A debriefing session was held with the translator to ensure they were not excessively affected by the sensitive content of the interviews. Basic demographic data were collected to allow for description in the analysis of patterns (Mason, 1996). The numerical data collected with the APCA Africa POS and POS-S tools were entered into an excel spreadsheet. Transcripts and data collection tools were anonymised by removing any indicators of names or places of residence. Care was also taken to anonymise health care professionals' transcripts as well.

3.4.10 Data Analysis

Use of computer-assisted qualitative data analysis software

Analysis was a complex and prolonged process. QSR NVivo version 10 analytic software was used to support data management and analysis. This software enabled organising and working on large volumes of qualitative data. All interview transcripts and the field notes for each patient were imported into Nvivo. Nvivo was mainly used for line-by-line coding, followed by focused coding and writing of some memos, but most memos were written manually. In this software, line-by-line coding was done by labelling selected texts from the transcripts with a name (code) that depicted the theme in that text. These codes were stored in files in Nvivo known as nodes. Once all the text of the transcripts had been organised under different nodes, Nvivo facilitated the quick review of the nodes which was done by the researcher clicking on the nodes and reading the text contained in it to ensure the text matched the code name or the theme. Nvivo was also useful in grouping similar nodes into broader themes creating second order codes and nodes. The grouping of texts of data from different

participants together under a node in Nvivo, also simplified the process of writing up the findings because quotes from these sections could be quickly called up to back up a theme. QSR Nvivo software also facilitated comparison of events within the same node among different participants providing another level of analysis. A sample of the coding process and the coding tree in Nvivo used in this study is shown in Appendix ten.

Use of techniques of grounded theory

The Grounded theory approach is that of an iterative process of sampling and analysis. Data collection and analysis are done concurrently. The analysis tends to move away from description to abstract theory, with the theory being grounded in the data (Green and Thorogood, 2009). Methods of qualitative data analysis from Charmaz's grounded theory approach informed the data analysis (Charmaz, 1995). Charmaz proposes the use of grounded theory principles in flexible ways and not necessarily as a package (Charmaz, 2006). Techniques from Charmaz' approach to grounded theory used in this study included theoretical sampling, line-by-line coding, focused coding, theoretical coding and the constant comparative method. The analysis was carried out according to the research question and objectives and across the identified and emerging thematic areas.

Coding

Following the completion of the first two interviews, data were translated and transcribed and coding was carried out for the first two transcripts to determine the content of interest and the direction the analysis was taking, in order to inform further sampling and analysis. Following this, at the end of each interview the same process was followed until the sample size of 21 was achieved where it was felt that sufficient data had been generated to meet the aims and objectives of the study. Data saturation is a concept often used to determine sample sizes in qualitative research but this has been criticised for invoking a more positivist model of qualitative research and some argue instead for enough data to tell a rich story, an argument employed in this study (Braun and Clarke, 2013). The analysis involved listening back to the recordings to clarify meaning and to listen for intonation and pauses and recall of the interview situation. My personal assumptions were acknowledged to allow coding to evolve that was not based on assumptions but reflected what was really there.

Based on Charmaz prescription (2006), initial coding was done 'line-by-line' in order to remain open to the data and get detailed observations of people, actions and the setting (Charmaz, 2006). Charmaz contends that line-by-line coding reduces the likelihood of researchers imposing their pre-conceived ideas on the data and it facilitates generation of new ideas. It also helps the researcher to identify processes easily and gives the researcher leads to pursue (Charmaz, 2006). Line-by-line coding did not necessary mean every line would be coded if it did not have analytical sense but it was a way of ensuring thorough analysis of every word and sentence. Line-by-line coding of all the first series of interviews generated 317 provisional codes. Each code was assessed further and reviewed for its fit with the segments of data and data was reallocated or codes renamed if deemed necessary. Some codes that had similar meaning and content were merged. Contradictory ideas were sought for and coded to refine emerging explanations.

Focused coding followed line-by-line coding and was used to synthesise and explain larger segments of data. Initial codes that made the most analytical sense to categorise data were retained. Focused coding helped to condense data. These codes were compared with the data and with each other (Charmaz, 2006). Focused coding helped to analyse for syntheses and larger explanations (Charmaz, 2006), hence moving codes from a descriptive level to a more conceptual ones. The transcripts were re-read to ascertain that the themes reflected what is contained in the transcripts and if data had been missed out it was coded. Codes were tested by having my supervisors review the transcripts for the purpose of triangulation and cross-validation. Field notes written during the interviews were integrated into the themes to help develop concepts and theories.

The final stage of coding was that of theoretical coding. In this stage, each of the codes generated in the focused coding were examined to determine how they related to each other as hypotheses to be integrated into a theory (Glaser, 1978). The researcher returned to the literature and identified theories that would help explain the data. Theories of biographical disruption by Bury (1982), narrative reconstruction by Williams (1984. Bury, 1991), the illness explanatory model of Kleinman, Eisenberg and Good (2006), the trajectory model (Corbin, 1998),and treatment work by Strauss et al. (1982) were all found to explain most of the data. Memos were written throughout the interview process and during analysis, these were incorporated into the

codes and categories and formed the basis of conceptual development (Charmaz, 2006) and were useful in writing up the discussion.

Constant comparative method

Constant comparison was employed throughout the coding process in order to identify similarities and differences by comparing data with data, and incident with incident of a participant, within the same interview and in different interviews of the same participant over time. Comparison was also done with all participants across the group (Charmaz, 2006) which helped in identifying patterns and contrasts.

Longitudinal analysis

For the longitudinal analysis of this study the approach to analysis of qualitative longitudinal interviews proposed by Thomson and Holland (2003) was used, along with some of the questions proposed by Saldana (2003) which facilitate exploration of change over time when conducting qualitative longitudinal analysis.
Thomson and Holland's approach (2003) to qualitative longitudinal research proposed looking at data cross-sectionally and longitudinally. Analysis in their study was done at the end of each interview for each participant and a summary of the analysis was written for each round of the interview. At the end of the longitudinal interviews all the analyses for each of the serial interviews for each patient were drawn together to form a 'case profile' and to compare themes across time. Cross-sectional analysis was also done for each round of data collection for all participants' interviews (each group of serial interviews) to capture each moment in time (Thomson and Holland, 2003). Although all the patients' interviewed were defined as having advanced HF, they were at different stages of their illness hence the appropriateness of the cross-sectional analysis of all interviews, as these '*capture moments in time which focused on biographically structured temporal themes*' (Thomson and Holland, 2003 p238). These moments in time for this study were different set points that stood out for all participants in the interviews (for example during the time of diagnosis, during the time of treatment and during the time of dying). Emerging themes were identified at those time points as a way of looking at developments over time and to make comparisons across the sample based on different factors (Thomson and Holland,

2003). Themes were compared for all patients in the group at a fixed time and over time but also for individuals over time.

Analysing the POS

Data collected from the APCA African POS and POS-S were used to complement interview data in mapping the changes in multidimensional experience over time for each participant to identify if there were any emerging patterns. Data from the APCA African POS and the POS-S on the prevalence of each of the multidimensional needs at the three points of interviewing were summarised in terms of proportions (percentages). Mean APCA African POS and POS-S scores for the severity of each item were determined at the three points of interviewing to map changes in the groups over time.

Summary

A qualitative research design was found most suitable for exploring the complex nature of the illness experience and for providing a holistic understanding of the phenomenon. Some tenets of the constructivist grounded theory methodology and pragmatism were employed, underpinned by a constructivist theoretical perspective and a subtle realism ontological stance. Serial qualitative in-depth interviews complemented with the APCA African POS were chosen as the most appropriate methods to meet the study aims. Patients were purposively sampled from the cardiology ward based on criteria that reflected the local demographic characteristics and were recruited if they met the eligibility criteria. Health professionals involved in the care of HF patients were recruited. Data were analysed based on some tenets of the constructivist grounded theory approach. Rigour and ethical conduct of the study were ensured.

CHAPTER FOUR

4.1 Participants and interviews

This chapter will describe the process of recruitment and interviewing participants during the research period to facilitate the interpretation of the findings.

4.1.1 Study profile

Thirty-five patients were approached who met the inclusion criteria. Two patients could not speak either of the two languages in which the interviews would be undertaken (English or Luganda) and two patients homes were out of the 30 kilometres radius span from Kampala, thus follow-up interviews would not be feasible, and therefore could not be included in the study. Information sheets were given to thirty-one patients. Five participants declined to consent to the study - three reported having been involved in another research before that and were not ready to answer more questions, and two did not give any reasons for declining to consent. Five patients were excluded because they were too ill or were too breathless to talk, or had impaired mental capacity and were not able to comprehend the information sheet. The characteristics of those who did not participate in the study are summarised in Table 2 below. Twenty-one patients consented and were enroled for the study (Figure 3).

Figure 3: Flow chart of patient recruitment

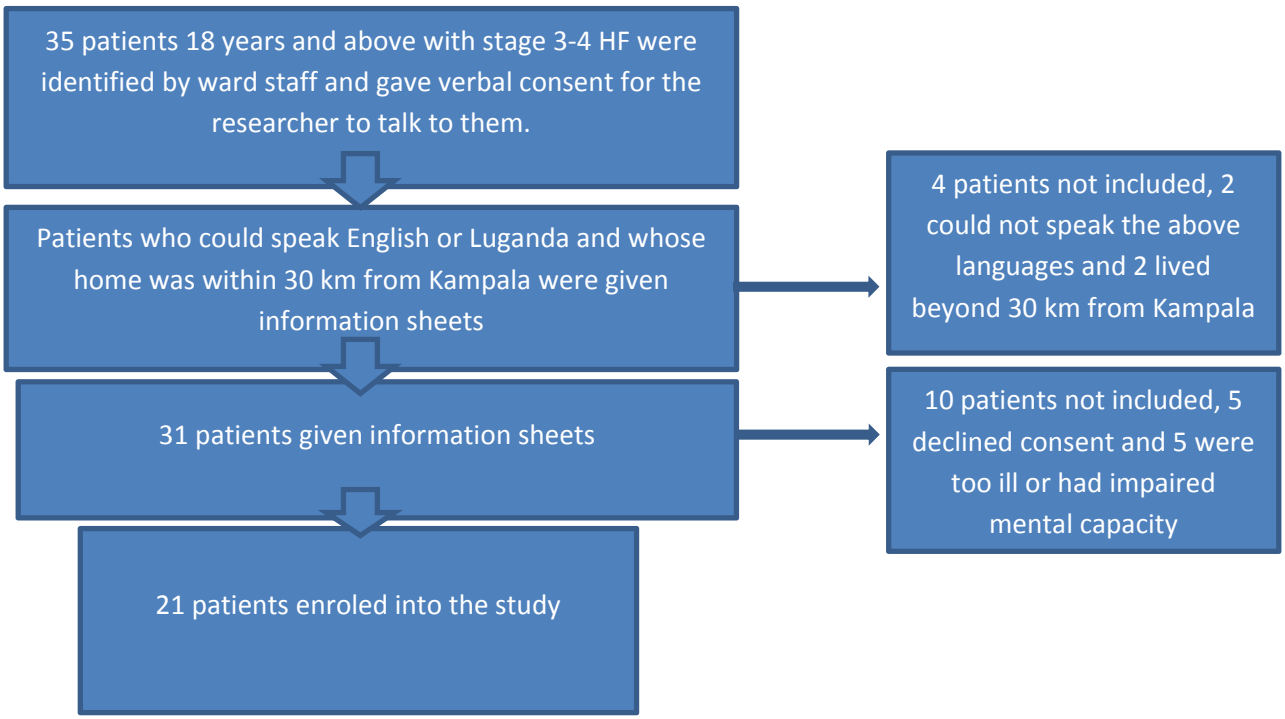


Table 2: Characteristics of those excluded from the study

Characteristic	Total
Age group (years)	
18-20	4
21-30	4
31-40	2
41-50	3
51-60	1
61-70	0
Sex	
Female	9
Male	5
Address	
From Kampala	12
Outside Kampala	2
Diagnosis	
Dilated cardiomyopathy	4
Endomyocardiofibrosis	2
Hypertensive heart disease	4
Rheumatic heart disease	3
HIV cardiomyopathy	1

4.1.2 Patient participants

A total of 21 patients with a diagnosis of HF were recruited and interviewed. Their basic characteristics are summarised in Table 3 below.

Table 3: Characteristics of those who participated in the study

Characteristic	Total
Age group	
18-20	1 (4.8%)
21-30	7 (33.3%)
31-40	3 (14.3%)
41-50	3 (14.3%)
51-60	6 (28.6%)
61-70	1 (4.7%)
Sex	
Female	15 (71.4%)
Male	6 (28.6%)
Education level	
None	5 (23.8%)
Primary	8 (38.1%)
Secondary	7 (33.3%)
Tertiary	1 (4.8%)
Marital status	
Single	8 (38.1%)
Married	6 (28.6%)
Widowed	5 (23.8%)
Separated	2 (9.5%)
Occupation	
Student	3 (14.3%)
Small business owner	4 (19.0%)
Subsistence Farmer	9 (42.8%)
Manual labourer	1 (4.8%)
Employed by others	3 (14.3%)
None	1 (4.8%)

Diagnosis	
Dilated cardiomyopathy	4 (19.0%)
Endomyocardiofibrosis	2 (9.5%)
Hypertensive heart disease	6 (28.7%)
Rheumatic heart disease	7 (33.3%)
HIV cardiomyopathy	2 (9.5%)
Ejection fraction	
≤30	7 (33.3%)
>30	6 (28.6%)
Not estimated	8 (38.1%)
Address	
From Kampala	7 (33.3%)
Outside Kampala	14 (66.7%)

Most of the patients were clustered in the age groups of 21-30 years (33.3%) and 51-60 years (28.6%). There were 15 (71.4%) females and six males (28.6%). Eight of the participants (38.1%) only had primary level of education and five did not have any formal education (23.8%). Three of the patients were students (14.3%) and the rest (85.7%) had low-income jobs. Seven patients had an ejection fraction of less than 30 (33.3%), six had an ejection fraction of 30 or more (28.6%) and in eight (38.1%) the ejection fraction was not estimated either because the Echocardiography was not done or because the bedside echocardiography used could not estimate the ejection fraction as it was of very old technology. In Mulago hospital those who cannot afford to pay for echocardiography with newer sophisticated machines, can have a bedside echocardiography done. This machine was a donation made to the hospital to enable visualization of structural heart defects but it is unable to estimate the ejection fraction. Most (66.7%) patients came from outside Kampala. Mulago Hospital is situated in Kampala district but being a national referral hospital, it receives patients from all over Uganda. Three patients (14.3%) did not have a family carer taking care of them in hospital and did all their care themselves or had to be supported by ward staff and fellow patients. Most of the carers (38.1%) were children of the patients and this often was observed in older female patients who were being taken care of by their

daughters. Other family carers included siblings (19%), parents (14.3%) and partners (14.3% - 2 wives and one husband). The details of each patient, their diagnosis and social demographic characteristics are summarised in table 4 below.

Table 4: Details of patients' sociodemographics and disease condition

Patient	Sex	Age	Education level	Occupation	Main carer	Diagnosis	Echo and ECG findings	NYHA	Comorbidity
1	Female	68	Primary	Subsistence farmer	Daughter	Dilated cardiomyopathy	Degenerative aortic valve disease moderate AS and AR. EF= 23%,	4	osteoarthritis
2	Male	18	Secondary	Student	Brother	endomyocardiofibrosis	Severe hypokinesia, dilated heart chambers. EF 28%.	4	none
3	Male	53	Primary	Carpenter	Wife	Hypertensive heart disease	Thickened left ventricular posterior wall.Dilated heart chambers.Minimal pericardial effusion. EF =33.8%	4	HIV on antiretroviral treatment, Hypertension
4	Female	45	Primary	Cleaner	Son (18 years)	Hypertensive heart disease	Dilated poorly contracting Left ventricle with EF= 35% Normal diastolic function.ECG ; Left Ventricular Hypertrophy	4	Hypertension

5	Female	32	None	Subsistence farmer	Husband	Endomyocardiofibrosis with rheumatic heart disease	Fibrosis left ventricle overiding left ventricle predominantly Endomyocardiofibrosis, also Rheumatic heart disease with MR, TR	4	none
6	Female	55	Secondary	Tailor	None	HIV associated cardiomyopathy	severe MR and AR EF=45%	3	HIV on antiretroviral treatment
7	Female	23	Primary	Waitress	Sister	HIV associated cardiomyopathy	Severe systolic failure mild MR. EF=18%	4	HIV on antiretroviral treatment
8	Male	22	Tertiary	Student	Brothers	Dilated cardiomyopathy	Dilated left chamber with poor systolic function. EF= 18%	4	None
9	Female	55	None	Subsistence farmer	Daughters	Dilated cardiomyopathy	Severe systolic dysfunction EF=31%	4	None
10	Male	50	Primary	Brick maker	Wife	Dilated cardiomyopathy	Severe systolic dysfunction	4	None
11	Female	60	Secondary	Small business	Daughter	Dilated cardiomyopathy	ECG: Left ventricular hypertrophy	3	None

12	Female	21	Secondary	Bar waitress	None	Hypertensive heart disease	left Ventricular Hypertrophy, mild pericardial effusion	3	End stage renal failure not on dialysis, hypertension
13	Female	38	None	Small business	Daughter (17 years)	endomyocardiofibrosis	Dilated right ventricle and atrium,Pulmonary hypertension severe Tricuspid regurgitation EF= 50%	3	Ovarian cyst
14	Male	22	Secondary	Student	Mother	Rheumatic heart disease	Dilated Left ventricle with poor function, severe MR and TR, Pulmonary hypertension EF =30%	4	None
15	Female	20	Primary	Subsistence farmer	Sister	Rheumatic heart disease	Hockey stick anterior leaflet, post leaflet tethered to post wall moderate to severe mitral regurgitation	4	None
16	Female	45	None	Unemployed	Daughter	Rheumatic heart disease	Not done	3	None

17	Female	39	Primary	Subsistence farmer	None	Hypertensive heart disease	Not done	4	Hypertension
18	Female	55	Primary	Subsistence farmer	Daughter	Dilated cardiomyopathy	ECG; Left bundle branch block. Echo not done.	4	None
19	Female	26	Primary	House wife	Mother	Rheumatic heart disease	MS and severe Atrial fibrillation, dilated left atrium, mild MR trace AR	4	None
20	Male	24	Secondary	Student	Mother	Hypertensive heart disease	Mild leventricular hypertrophy, bilateral atrialdilatation, severe left ventricular impairment, hypokinesia of posterior wall. EF= 21%,	3	Chronic kidney disease
21	Female	43	None	Subsistence farmer	Daughter	Rheumatic heart disease	ECHO not done	4	None

EF=ejection fraction, MS=mitral stenosis, MR=Mitral regurgitation, AR=aortic regurgitation, AS=aortic stenosis,TR=tricuspid regurgitation

4.1.3 Family carers

Nine patient family carers were interviewed (seven female, two male) including four daughters, three siblings, one parent and one partner. Family carers were mainly involved in the bereavement interviews (8) and a few participated in dual interviews with their patients (3) when asked by the patient to help answer some questions. Two family carers were involved in both the dual interviews with the patients and the bereavement interviews.

4.2 Patient and family carer interviews

A total of 48 face to face interviews with patients and their family carers (21 interviews in the first series of interviews, 13 interviews in the second series of interviews, six interviews in the third series of interviews and eight bereavement interviews) were conducted. Thirty-six interviews were conducted with patients alone, four interviews were paired (patient and family carer) and eight interviews with carers alone (bereavement interviews). The APCA African POS was administered at the end of all 40 interviews with patients. This checklist was completed using only patients' responses. Phone conversations were made to follow up patients every month until the end of the study. A summary of the interviews and the phone conversations is given in table 5 and the graphical representation of the interviews and the phone calls is attached in the appendix nine.

Table 5: Interviews conducted and phone conversations held over the course of the study

Interview/ phone conversation	***Int. 1**	****Phone conv month 1**	**Phone conv month 2**	**Int. 2 month 3**	**Phone conv. month 4**	**Phone conv month 5**	**Int. 3 month 6**	*****Brvmt int.**
Number of participants at the time/patients taken forward from last interview	21	21	18	16	16	15	10	11 known to be dead
Total interviews /phone conversations	21	9	11	13	10	8	6	8
Paired interviews (patient and carer)	3	N/A	N/A	1	N/A	N/A	None	
Patients not accessible on phone	N/A	9	5	3	5	4	4 Lost to follow up	3 carers declined
Cumulative Number known to be dead	N/A	3	5	5	6	11	11	
Location of patient at time of interview	21 hospital	6 home 3 hospital	8 home 3 hospital	6 home 7 hospital	6 home 4 hospital	4 home 4 hospital	3home 3 hospital	

* Int-interview, **Phone conv- Phone conversation, ***Brvmt –Bereavement interview N/A- not applicable

4.2.1 First series of interviews

All of the first series of interviews (21) were conducted in Mulago Hospital. Informed consent was obtained from all participants before interviews commenced. By the time of the first interview participants had lived with the illness for an average period of 3.1 years. The range of time they estimated to have lived with HF, before the first interview, was 3 months to 6 years.

4.2.2 Second series of interviews

The study protocol was for second interviews to be conducted three months after the first interviews or earlier if, after the monthly telephone conversation, patient's health status had changed significantly to necessitate hospitalisation or to change their functioning status. By the time of the second interview five deaths had been reported during the monthly phone calls, leaving 16 patients to interview. However when calls were made to the patients only 13 were contactable. After attempting to trace the patients for one week they were registered as lost to contact, as patients did not have physical addresses, they only gave me information on their home villages, and their phones went unanswered. In most of Uganda there are no clear physical addresses as roads do not have names and access is dependent on the community. Appointments were made with the thirteen participants to visit them at home or in hospital. All 13 participants gave written consent to participate in these interviews. Twelve were individual patient interviews and there was one paired interview of a patient and their carer. Of the thirteen interviews, six were carried out in participants' homes and seven in hospital. The seven interviews held in hospital were for those patients who were hospitalised due to a worsened clinical state. Five of the thirteen interviews were conducted at three months as planned and eight were conducted earlier due to a worsened clinical state. The second series of interviews were aimed at understanding how participants needs and experiences changed over the trajectory of the illness and how they lived with their illness over time, and to explore the patients' experiences prospectively when on treatment.

4.2.3 Third series of interviews

The third series of interviews were scheduled for six months after the first interview but similar to the second interviews, some third interviews were done earlier if it was

detected from the monthly phone calls that there was deterioration in the clinical state of the patients after the second interview. Eleven patients had died by the time of the third interview, it was therefore anticipated that 10 third interviews would be undertaken, however it was only possible to access six patients - four patients could not be accessed on the phone after attempting to contact them over a period of two weeks. All of the six patients consented to take part in the third interviews, three of these interviews were conducted at home and three in the hospital as the participants were in hospital at that particular time. All interviews were individual interviews without the patient carers. The third interviews were aimed at understanding patients experiences, needs and concerns during the dying phase as the literature from SSA had suggested that mortality for all stage of HF at 6 months is about 20% for all heart failure (Damasceno et al., 2012) and survival in advanced HF is about 50% at 1 year (Friedrich and Böhm 2007). I anticipated that in our setting where HF patients present with advanced disease for care the 6 month survival may be similar to the one year survival in settings where HF patients present early. Therefore, it was projected that at this point in their trajectory many patients would be in the dying phase.

4.2.4 Bereavement interviews

Eleven patients (50%) died during the study, six in hospital and five at home. Eight bereavement interviews were done out of the 11. Three bereavement interviews were not done. One of these carers reported she had moved back to her home area after her mother's death which was very far from Kampala and the other two carers for the deceased patients did not feel comfortable having an interview after their loved one's death and so declined. They felt it would be very painful to re-live the memories of the last days of their loved ones. The researcher often found out about participants' deaths on making the monthly phone calls or for those patients in hospital the nurses informed them. Three deaths happened one month after the first interview, by the second month six deaths, nine deaths at three months, ten deaths by month four, and 11 deaths by month five.

Bereavement interviews were aimed at understanding the dying experience in those with HF in Uganda and the needs and concerns of patients at this time and the type of care received. These interviews were to complement the third serial interviews and give a broader picture of this phenomenon of dying of HF. After finding out that the patient had died, usually when making the monthly call, condolences were expressed

to the family carer who had received the phone call. Another phone call was made one month later to the family carers to ask to visit them if they wished to talk about the deceased. If they accepted, the visit was arranged and during the visit a sympathy card was given during the visit and the carer was asked if they would care to be interviewed to talk about their deceased patient any time in the future. When they consented a date was set for the interview and written consent was gained. Most carers felt ready to be interviewed at the time of my visit and they were then given more information about the study and it was emphasised that they could opt out if they did not feel comfortable.

4.2.5 Phone conversations

A total of 38 phone conversations were conducted with patients or their family carers at months 1, 2, 4 and 5 following the first interview. Eleven phone calls were made to bereaved carers after learning of the patients' death. Telephone conversations with patients or their family carers were held every month as a way of building and retaining a relationship with the patients, but also to provide an alert when there was a change in health status. Significant changes in health status, such as that leading to deterioration in function status or requiring hospitalisation or if there was perceived distress in other non-physical dimensions on the phone conversation, were a trigger for a subsequent interview to be done earlier than scheduled at 3 months or 6 months. For example, eight participants had their second interviews before the scheduled 3 months and six participants also had their third interviews before 6 months, because when a phone call was made to find out how it was found that their condition had worsened to warrant hospitalisation. The study aimed to capture their needs at these states when their clinical condition had changed.

4.3 Health professional interviews

Eight health professionals (5 doctors, 2 nurses and 1 social worker) working on the cardiology ward in Mulago Hospital were interviewed. Their experience working on the cardiology ward ranged from one year to 12 years as in table 6 below.

Table 6: Health professionals interviewed, their cadre and years of experience in cardiology

Cadre of health professional	Number of health professionals in the cadre	Years of experience in cardiology
Consultant doctor	2	≥10
Senior Medical officer	2	5-9
Medical officer	1	<5
Senior Nursing officer	1	>5
Registered Nurse	1	<5
Social worker	1	3

The most senior doctor interviewed had been a cardiologist for 12 years, and one doctor had 10 years experience, two doctors had five years experience and one two years experience. One of the nurses had worked on the ward for seven years and the other for one year. The social worker had worked with cardiology patients for three years. A higher number of doctors were interviewed in order to capture the specific nature of cardiology care. The nurses and social worker interviewed share their time in caring for other patients on the ward, which also has nephrology and pulmonology patients. In Mulago Hospital each medical ward has three specialised units and although there are specialist doctors on each unit who only work on that unit, there are no specialist nurses and the same nurses care for patients on the other specialised units. The health professionals' views in the interviews were not centered only on the participants in this study but on HF patients seen in Mulago Hospital in general and therefore the statements made by health professionals about patients may not have been referring to these particular patients interviewed. In Uganda because of the high patient doctor ratios patients are not assigned to a particular doctor or general practitioner and therefore personal continuity of care is rare.

CHAPTER FIVE

5.0 Introduction

This chapter presents the findings of the participants' experiences from the commencement of their illness, through their experience of diagnosis, and of living with their illness. This chapter will address study objective 1:

Objective 1: To map patients' experience of being diagnosed with, treated for, living and dying of heart failure in Uganda

Data presented here on the patients' experiences over the course of their illness were derived from the in-depth interviews and complemented with data generated using the APCA African POS and the POS-S tools. The tools were used to give a quantitative picture of the experience in a clinical context to support clinicians to embrace the research better. The experience of having HF appeared and was therefore captured as a journey. Every patient's journey appeared to have three distinct stages or landmarks which stood out in their own narratives. These included the beginnings of their illness that led to a diagnosis, the treatment stages and the journey to death. Therefore, the experience of patients with HF in Uganda was summarized as a journey with three phases: first the phase to diagnosis when patients began experiencing symptoms that led to recognition of illness, seeking care and then being given a diagnosis; secondly the treatment phase that involved living with treatment, managing treatment, a continued symptom experience while on treatment, use of alternative medicine and self -care; and finally all patients were moving towards death which was the third phase. In this study 11 participants had died by the time of the third interview. Those who died, died in different places, frequently having received different types of care during this phase. All the experiences in the three stages of the illness journey impacted on the different areas of participants' lives including their understanding of their life and the illness, their psychological, spiritual and social experiences. These experiences are detailed in the sections below.

5.1 The journey to diagnosis

For 17 out of the 21 participants, the onset of illness and coming to a diagnosis was a gradual process often starting with experiencing symptoms and becoming aware that these symptoms together were the result of a specific illness. For all patients this was a journey into the unknown.

5.1.1 Experiencing initial symptoms

Registering symptoms as significant usually began when the symptoms impacted on their well-being. Most symptoms experienced at the start of the illness were related to the cardiovascular system and were either a result of the underlying cardiovascular disease or HF. They included: chest pain, cough, breathlessness, feeling easily tired, palpitations, dizziness, fainting, intermittent claudication and body swelling. Most participants became aware of these symptoms when they were doing strenuous activities, but felt normal after they had rested. The symptom experience over time evolved from having a single symptom to developing a complex sequence of new symptoms which were initially more present at night and gradually worsened and persisted all the time. The interval between these events varied widely with some having an acute presentation while others had a more gradual worsening of symptoms.

> *'I started by feeling burning in here (points at center of chest) when I had gone to dig, when I would strike the ground with the fork jembe I would feel a lot of burning inside my chest. I had to hold here (central chest) and I would press the chest a lot. Then the burning would slowly start decreasing and I would go on digging. When I went on digging, then this burning would recur and I would feel very severe pain inside then I would sit down until I felt better sometimes I would be harvesting food and would feel a lot of burning all over the chest and I would lie on the ground and then this pain would go down slowly and then go away….. After a while during the day I would do my work, but, at night I would not sleep. I would get breathless then I would sit up. Until after 3 months, here a swelling appeared here on the abdomen and I told my son I have this problem, the abdomen is swelling and that night I was taken to hospital because my condition was not good.' (Patient 1, Interview 1)*

5.1.2 Delay in illness recognition

Many participants did not attribute the symptoms they were experiencing to disease or severe illness because the symptoms did not seem severe enough to them. This study

identified several barriers to delayed association of symptoms to HF leading to delayed seeking of care.

Barriers to early association of symptoms with illness

A lack of awareness and understanding of the nature of HF symptoms so that when they appeared, participants could not interpret them.

> "I *really did not know much about this illness and so when it started I did not really take much notice" (Patient 20, Interview 1)*
>
> *"I did not know how it felt to have heart disease, how it pains*" *(Patient 1 Interview 1)*

The intermittent nature of symptoms and an overall sense of healthiness especially when not engaged in manual work.

> *"I did not understand, initially I thought it is something that has come and will go because it would come and if I stood and rested it would then go away then I would start walking again, just like that". (Patient 8, Interview 1)*

A belief that general functional decline was normal as one gets older.

> *"I thought maybe this menstruation coming to an end is associated with some problems of the heart ….we are told that when you reach menopause you get problems, you get a lot of heat, you sweat and all those symptoms I had them.* A*s you grow older some things change in your body, you cannot be the same as before when you are young so I thought that was the problem' (Patient 6, Interview 1).*

Young people talked of it being a temporary change in health because of normal life transitions, for example teenagers becoming adults. This was also because there is a strong view that chronic illness is not expected at this age. Coexisting conditions also deterred the recognition of the illness, one HIV positive participant noted:

> " *I did not understand what was going on I thought it may be the HIV medicines I was taking" (Patient 6, Interview 1)*

Another was influenced by her pregnancy and received advice from a traditional birth attendant that her symptoms were normal:

> *'During this pregnancy initially I was well but about the eighth month of pregnancy I felt so heavy. I used to lift a pot of food and put it on the fire but at that time I could not, everything I lifted the heart started beating a lot and subsequently everything I did my heart would beat so much. There were some women, the traditional birth attendants I went to one of them and explained my situation and she said, no it is okay the child has a normal lie in the*

abdomen (she coughs) but might be big or is seated in a lot of water. (amniotic fluid) That's what she told me and so I took it that way.' (Patient 5, Interview 1)

Symptoms that were directly linked to the heart were more likely to be interpreted more serious than those linked to other parts of the body. For example, one participant whose first major symptoms were palpitations immediately sought health advice, as though such symptoms must be serious.

"*This illness started with my heart I would feel like I am scared and it would beat a lot. Then I was taken to several health facilities and they checked me" (Patient 21, Interview 1)*

However, those whose first symptom was a cough or pain were more likely to assume that their illness was minor regardless of how unwell they felt:

"*Because of the cough I thought it was a common cough." (Patient 19, Interview 1)*

"I thought it was the normal cough or cold or allergy to dust" (Patient 7, Interview 1)

"I thought it was the mere cough which came on its own" (Patient 4, Interview 1)

Some participants explained that they thought their problem was caused by witchcraft or 'local' disease rather than being a biomedical problem and only local treatment would help. This was particularly the case when they had symptoms of swelling which are predominantly interpreted as witchcraft in Uganda.

"*As you know in the village people thought I had been bewitched, I even tried and went to a witch doctor" (Patient 13, Interview 1)*

"Most people you told would say let us try our local herbs stop taking western medicine, I have my local healer who can help." (Patient 8, Interview 1)

"The illness resulted from worrying a lot … I had a problem with another woman in the market , she accused me of being in love with her husband and she said I am going to bewitch you and burn up your children, you will see you will learn your lesson." (Patient 5, Interview 1)

"My aunt, she thought I might be bewitched and some suggested that I go to traditional healers." (Patient 2, Interview 1)

Often a number of factors existed simultaneously, making self-assessment complex. These barriers highlighted important themes in this research that is a population with

limited or no health literacy and the influence of culture and beliefs on decision making in health.

5.1.3 Seeking medical care

On average, patients lived with a range of indicative symptoms for 3 months before approaching a health professional. Seeking health care was usually triggered by a variety of circumstances. Seeking care was triggered by having what patients and the community considered as '*a significant symptom experience'*. For example:

a) A set of symptoms significantly impairing functioning.

When symptoms worsened to the point that they affected activities of daily living or grossly impaired functioning, especially among the household bread winners, participants sought initial healthcare advice. One participant who feared he had kidney disease explained:

> "*I used to have pain in the legs and the back, I thought it may be kidney disease or something but I just thought about it but did not make any effort to do what …to go to hospital, I just went on with my duties as usual until I felt worse, I felt chest pain, I could not carry things I used to carry I used to get something like difficulty in breathing …. I could no longer work, then I decided to go to hospital" (Patient 3, Interview 1)*

b) Symptoms legitimised by others

In some cases patients described how there needed to be a collective decision where families, friends and community neighbours had to affirm the patient's illness before it was acceptable for the patient to seek clinical care. Patients usually sensed they were unwell before this consensus and legitimisation was gained.

> *"During the first 3 months people would see me looking okay during the day but at night I was very unwell. I told my friends and neighbors that I could not sleep at night and when I tried to lie down I felt very bad.Until after 3 months , here (pointing to upper abdomen) my abdomen started swelling….. I told my son I have this problem, the abdomen is swelling and now I have a swelling here (points to upper abdomen) that night I was taken to hospital" (Patient 1 Interview 1)*

Visible signs of illness such as abdominal swelling as in the above quotation or leg swelling were needed to convince others that illness was real.

> **"***I did not really take much notice until it came to a time when I felt very weak and I was not able to reach school because I was weak and I had to stop on the way then go back home. I felt a lot of dizziness and body weakness, then*

one morning I noticed that my legs were swollen, so those who saw me noticed and commented but I thought it was a simple thing and that they will go back to normal but 3 days went by and there was no reduction in swelling and then I noticed a swelling in the abdomen here on the side of the liver, and I could not breathe well and when I walked a very short distance I would be out of breath so I decided to go to my mother because I used to live alone… So she immediately she took me to a nearby clinic" (Patient 20, Interview 1)

c) Symptoms associated with feared conditions

However, if patients had symptoms reminiscent of the symptoms of diseases that the community feared, for example tuberculosis, then family and community attitudes were very different.

"*My friends started telling me that I might have tuberculosis and took me to a hospital'' (Patient 5, Interview 1*).

Symptoms perceived to be life-threatening, those that presented acutely severe rather than gradually, and the participants' reactions to the symptoms also triggered early seeking of care.

I had a lot of pain I had to go to hospital and I coughed a lot and could not sleep" (Patient19, Interview 1).

"I cried a lot, then my mother and brother took me to Buluba hospital' (Patient 2, Interview 1)

Some symptoms, for example severe breathlessness were also recognised as needing clinical care,

"*I thought it was asthma, this is what actually prompted me to go to hospital" (Patient 3, Interview 1)*

"That *is why I came because as a human when you are breathless you know death is near" (Patient 16, Interview 1*)

d) Symptoms not amenable to local remedies

If symptoms were not amenable to simple medications or herbs then they were recognised as needing medical care.

"*I have had the problem for long but tried to push on, you know for us when we get ill we start with using local herbs , you are told take this but then I went on and started having palpitations and sweating , I got local herbs to help with the palpitations and they decreased then they started all over again. Then I felt my abdomen was swelling and then I went to a clinic*" *(Patient 10, Interview 1)*

"*I took some herbs but not from a witch doctor but I got them from a herbalist, who told me that I had got or been bewitched with a condition called ' entumbi' (associated with abdominal swelling) but I took them and did not get any change …. After a while my family realised it was not getting better and so they brought me to Mulago hospital*" *(Patient 13, Interview 1)*

Health illiteracy, lay beliefs and culture are illustrated from the above findings as being prominent themes in determining seeking of early medical care.

5.1.4 Reaching a diagnosis

For most patients, the period from initial presentation into the health care system, to that of receiving a diagnosis was a protracted one. This was especially true for those who first attended one of the lower level health units. Some participants described several visits to the health units before a diagnosis was made.

'I went to clinics, I also had a cough this one you heard me coughing I have had it for one year. Wherever I went I was told to submit sputum so that they can look for the disease but whenever they checked they failed to find what disease it was.

I; so when did they find out you had heart disease?

P; when I came here in February, they realised I was very sick and they said let's send her to Mulago, those in Mulago will be able to find the problem.' (Patient 15, Interview 1)

5.1.4.1 Barriers to timely diagnosis

Participants described how there were failures to make a correct diagnosis (probably due to lack of skills) and being given other diagnoses such as peptic ulcer disease, tuberculosis, asthma, HIV and pancreas problems, which for some patients led to the wrong treatment and further worsening, until they arrived at the national referral hospital of Mulago.

'The health worker first told me my pancreas had a problem, they admitted me in that clinic. I was in a bad state. They put on me drips of water (IV fluids). They gave me several bottles, then my legs started swelling and the whole body and face. I was in that clinic for 3 weeks but the situation did not change until my guardians decided that they bring me to Mulago and I was admitted' (Patient 8, Interview 1)

Other factors contributing to this protracted process were the presence of symptoms common to other diseases (such as cough and dyspnoea), leading to a confusing

clinical picture, lack of equipment for diagnosis and coexisting conditions such as pregnancy.

> *'I would go to the health centre but they had never checked me in a scan. They told me several things such as I was suffering from elephant fever,(elephantiasis) I would wake up with a swollen face and legs and I was told it was elephant fever I took medicines for this condition but it would not improve.' (Patient 12, Interview 1)*

> *'About the eighth month of pregnancy I felt so heavy. I used to lift a pot of food and put it on the fire but at that time I could not,everything I lifted the heart started beating a lot and subsequently everything I did my heart would beat so much. I went to the health center in Semuto, Nakaseke, where I gave birth to the child normally. The health care workers did not say there was anything wrong so I went back home.' (Patient 5, Interview 1)*

These findings demonstrate a major theme identified in delayed diagnosis once patients presented to health care centers which was the '*challenges in the health care system*' such as poor skills of the health professionals.

5.1.4.2 Responding to the diagnosis

Understanding patients' reactions to the information they received at the time of diagnosis provides a useful map in interpreting the experiences and needs of patients and their health seeking actions. Participants responded in different ways to the information about their diagnosis and different factors influenced their responses. Many participants were scared and worried due to previous beliefs and perceptions about heart disease, especially that it could not be treated in Uganda, that it required surgery in India or that it was incurable and so they felt their death was near. Others were surprised because they had previously believed that only sedentary people got heart disease.

> '*I was worried that I was going to die because people with heart disease if not taken to India for operation they do not survive.' (Patient 2, Interview 1)*

> *'I wondered, and thought eeh , because some time back they used to tell us that a person who does manual work does not get such illnesses so I asked myself, how did this come given the work I do? I was very surprised.' (Patient 3, Interview 1)*

> *'I got scared because, getting heart disease, the heart is one's life so if it is ill, you have to be in trouble.' (Patient 7, Interview 1)*

Some accepted the diagnosis stoically as something that they had to deal with and often compared themselves with those who were worse off than themselves.

'I had nothing to do about it, and am not the only patient with that type of sickness. You can take yourself to be badly off and you see another one who needs the support of your hand who is worse and you start comforting this other patient'. (Patient 4, Interview 1)

I did not mind, what can I do if an illness comes, if you get scared then you cannot take care of yourself, okay you may be worried about who will care for you if you are unable to care for yourself any longer, when you are too weak, but what do you do if an illness comes? Even if you get scared it cannot get better. (Patient 11, Interview 1)

Many participants felt confused due to inadequate information and they started inquiring for more information from other people around. This often created more confusion so that patients' narratives about their illness were not evidenced based.

'The first time they told me the heart was swollen; I was confused because, I had many questions because I thought it is swollen? What caused it? I was more confused. I started looking for information from people around and those with heart disease and every one came with their own ideas of the drugs I should be taking.' (Patient 8, Interview 1)

'It was hard and confusing for me, I started thinking is my heart going to burst then if it is swollen?' (Patient 9, Interview 1)

Some participants were indifferent to the news, probably due to how it was communicated by downplaying its gravity.

'I did not feel anything different because I knew it was an illness and they did not tell it to me in any bad way, they told me that I had heart disease.' (Patient 13, Interview 1)

A few participants were relieved and grateful that it was not what they perceived as a worse illness, such as kidney disease, illustrating the lack of understanding of the gravity of their own problem.

'I am happy and relieved because the results of the blood test for kidney problem are okay kidney disease is very bad illness. If they are okay the rest I shall endure all that comes, uumm I can accept diabetes because if you treat diabetes you can live, people with kidney disease really suffer a lot especially if they are poor. When you have kidney disease your life comes to an end, you cannot do anything, I see people on the sixth floor, who have the kidneys washed (hemodialysis) I wonder how they do it but they have to pay 250,000 shillings every time they do it. God has helped me not to have kidney disease.'(Patient 11 interview 1 -daughter had Diabetic nephropathy with end stage renal failure)

These patients' reactions reveal important themes that influence patients' response to illness including lay beliefs and knowledge and health illiteracy. In summary, the journey to diagnosis appeared as that of walking into the unknown with four themes standing out as important in influencing the experience of patients during this: the symptom experience, their culture and beliefs, health illiteracy and challenges in the health system.

5.2 The journey with treatment

Once patients sought care from either medical health care workers, or from alternative health practitioners, they commenced a different type of journey dominated by costs, expectations, hopes and disillusionment. This phase of the journey also revealed that patients were continuing to walk and learning to live with the unknown.

5.2.1 Experience of living with treatment

Participants spoke of the balance of ensuring adherence, whilst living with side-effects of the medicines. Participants formed different views about the treatments they were taking during the treatment process.

5.2.1.1 Managing treatment

Participants' narratives suggest that the management of treatment was interpreted by patients almost as another job altogether. It involved physical, social and psychological work. Most of the work was done to ensure adherence to treatment and managing side-effects of the medicines. The underlying theme in managing treatment emerged as coping with treatment.

Psychological work in treatment

Participants spoke of how onerous it was to take medicines every day of their lives and it involved a lot of determination and psychological work with oneself to get to a position of accepting to take the medicines regularly.

> *'Taking medicines every day is one of the biggest problems, because even some give up and die. If someone takes medicines for 20 years give them credit, they are committed. It is not easy to take medicines in the morning and in the evening, some are big pills for example some big pills you first look at them before you swallow them and contemplate whether to swallow them, it even makes you feel sad… when I take medicines for a long time I start fearing*

them, then I start dodging it. I just start hating it, I would prefer to be given an injection and get over and done with it.' (Patient 20, Interview 1)

Participants worked out ways of dealing with the burdens of treatment by employing cognitive, mental and psychological processes that included accepting the medicines, because that was the only way to feel better.

'It is not easy but because I know that my life depends on it I have no choice'(Patient 13, Interview 1)

Comparing themselves with others with conditions that needed daily injections such as diabetes mellitus made them appreciate how fortunate they were to take oral medications;

'How about those who have to inject themselves with drugs everyday, if they can do it why not swallow the medication because you cannot compare the tablets to the injection because the injection is painful'
(Patient 10, Interview 1)

Making the taking of medicine part of their daily routine and having a determined attitude to take medicines with the goal of improvement;

'I have put the medicines into my mind it is part of my life because I love my life very much .., even in this bag you may think I carry expensive things in it but it is just medications I them carry with me everywhere'.
(Patient 3, Interview 1)

Physical work in treatment management

Participants had to fit the medicines and their side-effects into their lives and activities so that they did not interfere with social interaction, but these adjustments often inconvenienced the participants. It involved pragmatic timing of taking of the medicines to ensure side-effects that affected social interactions were reduced, or occurred when they were not in public places or at work, but at home. Patients also had to come up with innovative ways of managing their environment so as to manage side-effects (such as passing out a lot of water at night) by having containers in which they would pass the water near them, as usually their toilets were outside the house and it would be difficult to make several visits there, especially in the night and when they were too weak to walk.

'It is because other people do not know how to use the medicines , if I see that during the day they will keep me moving to the bathroom and I have to go past people all the time so as to pass water all the time I use them at night and I just put a bucket near my bed.
I; how about your sleep?

P; I would rather not sleep because if I had taken them this morning I would have gone out of this interview several times. Sometimes I vomit the pills. I try to crush them and then take them…you really have to try this and that and be creative (Patient 1, Interview 1)

'I swallow because there is nothing I can do and if I am lazy no one will help me , it is my life let me do my best and If I fear them in the morning when I feel they will nauseate me I take them at night before I sleep.' (Patient 16, Interview 1)

Social work in managing treatment

Financial constraints dominated discussions around accessing treatment as participants and their families mobilised funds for their treatment in different ways, including selling their property and getting support from friends and some charitable organisations. Taking food along with medication also added to costs.

'As you know as a person in the village you have some animals you rear at home so I started selling them the chicken, the goats so that I could get treatment'. (Patient 5, Interview 1)

'It is also difficult because you kind of have to appeal to people to contribute and let them know you have to go back to hospital but have no means or financial support. Some will contribute to transport funds or you may find someone who will lend you the transport fare.' (Patient 9, Interview 1)

5.2.1.2 Experiencing side-effects

Most participants reported side-effects whilst taking their treatment. However, the side-effects were downplayed by the patients, possibly because they generally felt that these side-effects were not comparable to the degree of suffering they would have had if they were not on treatment. Therefore they felt that they had no reason to complain about them and they had to trade off the discomfort caused by the illness with acceptable discomfort due to the side-effects of the medicine in order to cope.

'If you need life you have to endure all the difficulties with the medicines in order to have life.' (Patient 4, Interview 1)

The most common side- effect was frequent urination, but for most participants this was a desired effect and they realised that without it they would not feel well.

'I like to pass out the water because you do not swell, but if you do not pass out urine you feel unwell. I feel unwell personally' (Patient 9, Interview 1)

Other side-effects included: vomiting, excessive thirst, headache, bitter taste in the mouth, feeling drunk and drying up and feeling as if you are shrinking.

'Sometimes I swallow the medicine and vomit it, sometimes it causes headache…. Some has a bitter taste' (Patient 12, Interview 1)

'The medicine makes me feel drunk' (Patient 16, Interview 1)

'The water medicine dries us up. It takes away even the water that should be in the body and makes you shrink.' (Patient 20, Interview 1)

5.2.1.3 Adherence to treatment

There were variations in participants' adherence to treatment, with some patients adhering to treatment 100%, the majority missing a few doses, and a small number self-reporting poor adherence to treatment. Having family support and being on treatment for other co-morbidities, specifically those on antiretroviral treatment for HIV, facilitated adherence to treatment. This may be because of the adherence counselling that is done before one starts on antiretroviral therapy and this may help with other medicines.

'My husband was there for me and helped me to get courage and he told me mama xxxx you have to be strong, you should take the medicines, take courage take the medicines and he would come in the morning and encourage me to take the medicines now I am used to taking them and whatever happens I have to take it.' (Patient 21, Interview 1)

Significant barriers to treatment adherence included:

-Lack of medicines in hospitals, coupled with the cost of purchasing medicines outside the hospital system through private clinics or pharmacies.

'They wrote for me these ones but I have no money to buy them.'(prescription has digoxin, Lasix and spironolactone and chloramphenicol)
(Patient 13, Interview 2)

-Day-to-day distractions, which led to forgetting to take the medications

'At times you may forget and miss, then you think to yourself it is too late to take the medicines it is past time for the medicines I shall take them tomorrow. But you cannot spend a week without taking the medicine.'
(Patient 1, Interview 2)

Participants' spiritual beliefs that emphasised that taking medication was a sign of a lack of faith in God, and faith was very essential for one to be cured.

'The pastors have been praying for me but most problems have changed now. Do you know that I do not take my medicines these days but my blood pressure is normal it surprises me too…… yes, but well it mostly depends on your faith, if they pray for you and you believe that you are cured .For those who still have problems he encourages you to continue with medicines but as long as

you accept that you are healed you will be, because healing comes from faith.' (Patient 20, Interview 1)

Some patients believed that some medicines failed over time, especially the diuretics, and this reduced their motivation to adhere to them. They explained their lack of adherence in different ways:

'Yes, but when things become worse, these tablets cannot work, even if you take thirty of them, you cannot get any difference.' (Patient 4, Interview 2)

'I think my body has become addicted to those tablets and they do not work on me any more so I had to stop them. They first gave me first 40 mg then they increased to 80mg but then I was still failing to pass urine. I got worse so I stopped them' (Patient 20, Interview 2)

The attitudes and views participants developed about the treatment they were receiving was also a significant barrier. Participants valued medications which they believed to reduce symptoms, such as water retention, over other medications.

' If I have those water tablets, you can deny me any other tablets but give me those tablets because they give a lot of relief' (Patient 1, Interview 1)

'Even the injectable medicine we buy in the pharmacy for passing out water we buy fakes but the one you give us here it is very strong and tough but the ones we buy are weak. It is stronger what we get here it make a difference. As for the tablets there is a time I swallowed 10 of them in a day but I did not pass out any water. May be I had a lot of water and they just dissolved in it. But in the past they used to work for me.' (Patient 6, Interview 3)

This was problematic when participants were on multiple medications and were guessing which ones improved symptoms, and sometimes they chose the wrong ones.

'These are the ones which help (points to ciprofloxacin) they help me pass a lot of urine, those (frusemide) were given to me but did not do anything…;yes the 10, the last time he came he was given 90 of the other and 10 of these (ciprofloxacin) but the former run out without making any difference, but the 10 made a difference and I even went back to buy more of them (ciprofloxacin) when they run out' (Patient 10, Interview 1)

In this example the participant believes that a short course of prescribed antibiotics was of more value than the diuretic he was on, thus stopped the latter, but continued to buy and take the former which was inappropriate.

Participants also preferred diuretic injections that helped them to pass out water over the diuretic tablets as they viewed these as more effective. Participants abandoned oral treatments when their symptoms worsened.

'Except the water tablets and the water injection the other medicines do not do anything. But the water tablets are weak, there are times when you swallow

then but you do not pass out the water you continue swelling and that is when you need an injection.' (Patient 6, Interview 1)

5.2.2 Using complementary and traditional therapies

Participants commonly used alternative medications alongside biomedical treatments, though this information was not initially volunteered. This may be because they sensed a tension between the different forms of care and the healthcare givers in Uganda. One patient withheld this information completely, until it was disclosed by their family carer at the end of the interview. Use of these therapies revealed the role lay beliefs play in influencing choice and the use of different treatments.

There appeared to be three ways that these patients used complementary and traditional therapies. Firstly, to take away evil curses or spells and for most participants this happened at the beginning of the illness, when they got symptoms that were unusual and that are associated with jumping over evil charms and in this case this was the first type of treatment they got.

'As you know in the village people thought I had been bewitched, I even tried and went to a witch doctor but afterwards I refused to go there anymore. He asked for 10,000 shillings and a chicken but I did not go back. I took some herbs but not from a witch doctor but I got them from a herbalist, who told me that I had got or been bewitched with a condition called ' entumbi' (associated with abdominal swelling)- but I took them and did not get any change.' (Patient 13, Interview 1)

The second way was concurrently with the therapies used in medical care, and patients used it to mitigate side-effects of the conventional medicine therapies or to enhance the effects of the conventional medicine. They tended to initiate these after being on conventional treatment for a while.

'I was told to buy the herb called the heart of the soil by a herbalist who cooked it for me and added some other herbs in it and told me to drink it. But now I see some improvement in the heart….yes, it is a good treatment for the heart, the one which has a strong smell, have you heard of the heart of the soil? It is like this, if the strength of the injection has gone down then you add in this herb but then you realise that when you take them together it removes all hidden illness and you get diarrhoea .You feel a bit better and then you can continue with the hospital medicine it is like mixing some meat with a bit of fat when you are eating.' (Patient 6, Interview 3)

'I have been taking some herbs I made myself to give me some energy, I have them here and I was told to take them to help me deal with the strong medicines , that will be given to me in the hospital.' (Patient 11, Interview 1)

Thirdly, as an alternative to the conventional medicines. Patients often started with using herbal treatments, but lost faith in them when their illness did not improve. Others used alternative medicine when they felt the conventional treatments were failing and this was often at the advice of other people.

> *'If I have not swallowed the medicines at night I swallow garlic, do you know it? I cut it into small pieces and swallow it like tablets, there I can sleep ….. It lowers the blood pressure as long as you eat enough food to make you full, you can swallow the garlic every day it has no problem. Dr.Ss the herbalist do you know him? He told us that if you swallow hot pepper it helps, as long as you take it and follow it with a drink of water.' (Patient 11, Interview 1)*

> '*They gave me the that native medicine when the illness had just started but aah it did not help' (Patient 18, Interview 1)*

5.2.3 Living with illness

The majority of participants described many uncontrolled symptoms even when receiving treatment for HF. The in-depth interview revealed mainly cardiovascular symptoms, and the APCA African POS and POS-S added value to these interviews providing a clinical picture of unmentioned symptoms and giving an indication of their prevalence and severity among the participants of this study. As in table 7 below:

Table 7: Symptom burden and prevalence of severe symptoms among participants over their illness course

Symptom	1st interview N=21 Prevalence of symptom n (%)	1st interview N=21 Prevalence of severe Symptoms (score ≥3) n (%)	2nd interview N=13 Prevalence of symptom n(%)	2nd interview N=13 Prevalence of severe Symptoms (score ≥3) n (%)	3rd interview N=6 Prevalence of symptom n(%)	3rd interview N=6 Prevalence of severe Symptoms (score ≥3) n(%)
Pain	17 (81)	11(52)	8(62)	8(62)	4 (71)	4(71)
Shortness of breath	21 (100)	20 (95)	10 (77)	9 (69)	6 (100)	3(50)
Fatigue	21 (100)	18 (86)	13 (100)	11(85)	6(100)	4(71)
Nausea and vomiting	18 (86)	4(19)	6 (46)	4 (31)	0(0)	0(0)
Anorexia	19(91)	13 (62)	10 (77)	10 (77)	3(50)	2(33)
Constipation	6 (29)	2 (10)	6 (46)	4 (31)	1 (16)	0 (0)
Mouth problems	11(52)	3 (14)	1 (8)	0 (0)	1(16)	1(16)
Drowsiness	8 (38)	6 (29)	6(46)	3(23)	1(16)	1(16)
Difficulty with mobility	21 (100)	17 (81)	12 (92)	10(77)	6 (100)	5(83)
Cough	13 (62)	11 (52)	7 (54)	6(46)	1(16)	1 (16)
Palpitations	5 (24)	5 (24)	3 (23)	3(23)	3 (50)	3 (50)
Oedema	19 (91)	17 (81)	6 (46)	6 (46)	2(33)	2 (33)

The table 7 above shows the different symptoms participants presented with and the proportion of participants with the different symptoms along with the prevalence of

severe symptoms. As noted above, the majority of patients experienced in addition to symptoms of the cardiovascular system, non-cardiovascular symptoms, including pain, anorexia, constipation, oral problems and drowsiness.

5.2.3.1 Impact of illness on the physical lives of participants

Participants' level of activity decreased as their illness progressively worsened. Patients described taking on lighter and lighter work until they were only able to carry out activities of daily living and eventually they were unable to do anything at all, including self-care, so that they became dependent on others for care.

> *'I used to feel easily tired on walking, when I lay flat I could not breathe well, I was coughing. Before that started I used to bend and was able to do some work like chopping wood but now I could no longer be able to do such work. Then the abdomen started swelling and it felt hot inside, you would think, they put in it hot water in it that burnt it. And because of this I would not sleep, except when I put a cold cloth on the abdomen to cool, it was very hot. Currently I cannot help myself, my mother cares for me I wake up and go and sit, the only thing I can do is to go out and sit, then sleep, I cannot even bend, I cannot not even bathe myself she bathes me, if I bend I feel so breathless every time I bend I have problems breathing, I breathe quickly.'*
> *(Patient 14, Interview 1)*

5.2.3.2 Participants' patterns of illness and level of functioning over their illness course

The in-depth interviews revealed that once a diagnosis was made and treatment for HF was initiated, the experience of their illness and the accompanying level of functioning took on 3 different courses. Firstly, there were those who got near complete resolution of symptoms followed by periods of a few months of stability with minimal or no symptoms. They returned to almost normal function, (although they could not engage in much strenuous work) interspersed with symptom recurrences and repeated hospitalisations, with less improvement on subsequent treatment leading to gradual reduction in function to just a few activities of daily living, and finally a phase of intractable symptoms where they were completely dependent on others for care.

> *'The doctor then referred us to New Mulago. We were told I had a heart disease. They started giving me injections and the legs went back to normal and the abdomen reduced but did not ever go back to normal. But I felt better and even went back home and started working as you know an adult cannot just sit without working even when sick. I even started preparing snacks and selling them to school children to get some money. But after some time I*

noticed that I was getting weaker and I could not even go up a hill. I would walk for a mile when going down hill but would not go much on a hill. After sometime I could not do anything any more I gave up making the snacks and just started coming here to get medicines in the clinic. Since last month I have never felt so bad in my life as now, I feel so weak I cannot do anything.' (Patient 5, Interview1)

On the second interview she said:

'*I now stay in bed most of time, I cannot walk without support.' (Patient 5, Interview 2 at home)*

On a phone call after a month she said:

'*I am much better now, I am able to walk, I can go out of the house, I have improved I can even cook some food if the children carry the pans for me.' (Patient 5, Phone interview month 5)*

Then during the interview at month 6:

'I became weak again, I cannot do any work, I just sit outside and listen or feel what is there but I struggle even to get there.' (Patient 5, Interview 3)

'Well what can she do now not much, she was able to do some work when she improved in the 8 months after the first treatment I told you about. But the illness came back.' (Carer patient 18 interview 1)

When we visited the patient on the second interview *she* said

'I feel so bad I used to do my work well, I would cut and pile a lot of banana leaves and load them onto a truck to sell in Owino market, I also used to grow and sell cassava, potatoes. I think about those days and how I am unable to earn any money now I Just sit at home. You start depending on what others can give you, even if they don't cook I eat my bought chapatti and a cup of tea and keep quiet, I just survive like that. You see how I look sometimes I want to bathe but I have no one to get me the water.' (Patient 18, interview 2)

The second course was of those who initially had minimal or almost no improvement with initial treatment and were dependent for the first few months, but gradually their symptoms improved, leading to improvement in function and return to work. This was followed by periods of symptom recurrence with decline in the level of function, interspersed with periods of well-being but deteriorating level of function until symptoms became intractable leading to total dependency.

'I did not get any improvement since I was discharged. By the time I got home from the taxi on the day of discharge my legs were so swollen, even people at home asked me why I had come back without getting better. My body continued to swell and now I cough alot and the abdomen is swollen, I cannot

even do anything for my family at home , I cannot do any work' (Patient 4, Interview 2 on rehospitalisation 1 month after discharge)

On her third interview on the phone after 2 months she said:

'I have not been bad, there was a difference, they changed the tablets now the heart feels lighter, even if I feel some pain but now even when I walk I feel lighter I have been able to make tea, cook food and the children find the food ready and I went back to work part time' (Patient 4, conversation on phone)

Then on the last interview at 6 months she said:

'*Iam not well at all, the cough has become worse, I cough more now a lot of foam and blood. Also my heart beats a lot these days I stopped going to work even I cannot do the little work I used to do but may be sometimes the children bring the food nearby and then I can cook it. They have to bring all things near to me then I can do a little work when I am sitting. I cannot even sleep at night whenever I lay flat I cough a lot'. (Patient 4, Interview 3)*

Finally, there were those with very minimal or no improvement at all with continued intractable symptoms since initiation of treatment until death and were dependent throughout.

'So they admitted me and I stayed for 2 days and I improved and they told me to come back in the outpatients' clinic to pick medicines, so I did so but even when I took the medicines even when before they run out, I would get time when the situation would worsen, I would cough a lot and then vomit and then get palpitations. I have been admitted 3 times, even when I take medicines regularly there is no change.. for the last 3 years, the longest I felt somehow better was for about 2 months….during the pregnancy I was so bad, after I could not even breast feed my child or even carry him. There is nothing I can do even if it is washing my children's clothes or bathing them I cannot do it. My mother has to bathe me, I get so easily fatigued even pouring water on myself' (Patient 19, Interview 1, died 1 week later)

The APCA African POS tended to demonstrate no significant changes in the experience of most symptoms over the 6 months, when the 3 interviews were done as shown in table 8.

Table 8: Mean POS scores for different symptoms over the illness course

Symptom	Mean score 1st interview (N=21)	Mean score second interview (N=13)	Mean score 3rd interview (N=6)
Pain	2.4	2.5	2.7
Shortness of breath	3.5	3.2	3.3
Weakness	3.7	4.0	3.4
Nausea and vomiting	1.7	1.5	0
Anorexia	2.5	3.3	1.9
Constipation	0.6	1.7	0.1
Mouth problems	1.2	0.1	0.6
Drowsiness	1.1	1.0	2.0
Difficulty with mobility	2.4	2.3	1.1
Cough	1.1	1.2	0.6
Palpitations	3.1	2.0	1.4
Oedema	3.7	3.3	3.4

5.2.3.3 Factors influencing changes in symptoms over the course of illness

The symptom course during treatment and physical response to treatment seemed to be influenced by the aetiology and severity of the illness at initiation of treatment with those with severe structural illness having less improvement. Other factors which influenced the symptom course included presence of new infections and co-morbidity.

> *'I commonly get coughs and colds from the children because they get these from school. As soon as I get it I know I am in trouble, it is what makes everything come back.' (Patient 5, Interview 1)*

Inadequate self-care due to health illiteracy, such as continued high water and salt intake and engaging in manual work.

> *'But it came back again and this is the reason I am here this time. But it is probably because I have been doing more work that I could. … I think I have been stressed a lot.' (Patient 20, Interview1)*

> *'Before when I used to take salt I would feel bad because I would get breathless but currently I eat it I do not get any problems. But I do not add raw salt. (Patient 11, Interview 1)*

Being pregnant:

> '*Even for my illness to get worse it was because I got pregnant another time, I was here on this ward and they treated me and I felt much better for about a year, then I got pregnant I did not realise I was even pregnant, I found out when the pregnancy was about 3 months, I wanted to have an abortion but had no money, ….after giving birth the problems of the heart worsened.' (Patient 17, Interview 1)*

Poor adherence to medicines, especially those which offer mortality benefit was also a factor. In the majority of cases the worsened symptom course and resulting loss of function was due to poor adherence to medicines or failure to get appropriate medicines which confer mortality benefit. Some participants improved with time when treatment doses were optimised.

> *'You see they never gave me these medicines, so I have been missing these tablets they only gave me one type not even the water tablets were given to me at least if those tablets were there I would be a little better. (Patient 6, Interview 2)*

5.2.4 Caring for self

Many participants took extra measures in addition to the treatment to ensure they improved their well-being, they felt they were in a battle with the illness and self-care was their artillery. Some of these measures were medically informed whilst others reflected their beliefs and the beliefs of the community. Self-care measures employed included:

What they considered as an appropriate diet.

> *'I heard over the radio that if you add raw salt to food this will cause water to accumulate around your heart so I avoid it. If I am at home I drink a lot, I take ribena, lucozade, and I can access tomatoes and care for myself. I use a lot of packed drinks. I try to eat well; sometimes the food you eat may not be good for a sick patient for example yams.' (Patient 1, Interview 1)*

Avoiding what they perceived as precipitating factors such as worry and alcohol.

> '*One should avoid things which scare or worry him, even when he is bereaved do not give the news badly because it may frighten them alot, so bring the news gently. Also these children who play and shout or make noise they frighten you and then you get palpitations. The food is difficult because one becomes very choosy, you may want something but by the time they bring it you no longer want it. This happens to me a lot.*' *(Patient 10, Interview 1)*

Having time to rest, adhering to treatments, having regular reviews in hospital and being physically active. The motivation for self-care was to avoid being dependent, and some participants felt more responsible than others if they cared for themselves.

> *'As long as I feel I cannot breathe, I cannot bend and when I find going uphill is very difficult, I come back to hospital. It is just a matter of time when all the impurities collect up in your body and then manifest, it is like he body sieves them , and when you come you come to remove the impurities and then you go home it collects up and the cycle repeats itself. When you bathe in a bathroom don't you wash it?'(Patient 6 interview 1)*

> *'But one important thing is that I wake up early and get my broom and sweep so that I can breathe in the fresh morning air and then I cook my food which I eat and then I can take my medication. Then I go on to rest a bit have a nap, then when I wake up I go and pick coffee berries in the garden, so I try to be physically active so that I do not become like porridge or to be ill as a prince or princess . Who would carry me; you would be bothering/ burdening your close people. That is it. I also walk around in the village, do evening walks. Now with the heart, they tell us to eat fruits, we should not eat salt, no water; this illness is so selective. I have been fighting my war. If you do not care for your life you are gone with this illness.' (Patient 6 interview 3)*

Participants also reported that they had different limitations to self -care such as: financial constraints because participants could not afford the diet they felt was appropriate; poor appetite; and social circumstances which did not allow them to have separate meals which were free of salt.

> '*They told me to eat little salt … this can only happen sometimes if I have cooked ,but sometimes when the children cook they put in much salt, so sometimes I fail to eat it…The self-care is generally not so good.' (Patient 5, Interview 1)*

> *'You know what is in the village, you eat what is available, and you cannot inconvenience those caring for you that I want this and that when they do not have the money to buy it.' (Patient 13, Interview 1)*

Other limitations were the side-effects of the medicines and sometimes their knowledge and understanding of what is healthy living, which emphasised the importance of fluid in the body.

> *'They tell us to drink less but remember the other medicine that they give us dries the throat you have to drink when you take it, so it is a bit difficult to balance the two, you have to be careful. Because at my age I cannot eat a lot I drink more. So I have to drink what will help me gain strength? When I eat in the morning then I do not eat again. Therefore I have to drink, after all even when we eat solid food it turns into fluid in the body even fluid remains fluid in the body so it is the same really eating or drinking. Most of our body is made of water. It plays a big role in our body.' (Patient 6, Interview 3)*

This quote shows how self-care was influenced by lay beliefs and health illiteracy. Participants felt that dietary restrictions had left them with no option of what food to eat as some had other co-morbidities, which had already restricted their diets.

> *'We should eat little salt, but you know food without salt food is not really tasty and so you lose appetite, one should not drink juice, not eat beef because it can raise blood pressure so you are left with no choice even when you get the money you get hungry but all you want to eat has been denied you. You want to eat but there is no choice. It is not easy to eat fish every day it is expensive and you cannot eat it every day.' (Patient 20, Interview 1)*

> *'They stopped me from eating some foods because of the kidney problem and now also others because of the heart but did not specify what I should eat, so most times I just take tea only.' (Patient 12, Interview 1)*

Participants' experiences in the journey with treatment revealed a life of living with the unknown with themes of: a life dominated with symptoms and impaired functioning; financial and social challenges; health system challenges; health illiteracy; lay beliefs influencing self-care; treatment management and adherence; and learning to cope when living in the unknown.

5.3 The journey to death

Patients' experiences as they approached death

All of the accounts on this stage of the journey except one, were obtained from bereaved carers. The one exception was from a participant who was re-hospitalised and died a few days later in the hospital. By the end of the study, 11 participants had died and 8 family carers consented to have bereavement interviews.

The symptom experience during the stage of dying

Interviews with bereaved carers and one patient at the time of death revealed that as participants approached death, in addition to HF symptoms, they developed symptoms resulting from the complications of HF and its treatment and symptoms which indicated that death was imminent. Symptoms and signs at the end-of-life included: excessive weakness, changing level of consciousness and ultimately complete loss of consciousness, difficulty in breathing, convulsions, low or absent blood pressure, pain, feeling loss of power in the limbs, worsening palpitations, coughing up blood, swollen and cold feet, restlessness, constipation and abdominal distension.

> *'She did not get any better, she continued to swell and her arms and legs burst and started leaking fluid,.. she died at home.' (Bereavement interview family carer, Patient 1)*

> *'The heart, it became wild and started beating a lot even when you sat next to her you would hear her pulse. Then we took her back to hospital, she was much worse then she could not even sit up, when you were with her she needed to lean on something or someone, her legs were swollen. So they put her on oxygen they really cared for her and treated her but it all failed.' (Bereavement interview family carer, Patient 16)*

> '*We also do not know what happened but it was on EID day, she stopped talking and the next day she could not wake up and so we brought her back to hospital.' (Bereavement interview family carer, Patient 9)*

5.3.1 The process of death

The data generated revealed two typologies of dying. The first was through a gradual worsening of symptoms to an intractable state, associated with disability and dependence, followed by death. In this situation some family carers understood what was happening and therefore expected death and were prepared for it, whilst others remained optimistic about cures and did not anticipate that death was imminent.

> '*She was very ill, all her body was swollen, and she could not sleep at night. She did not get any better since you last came to visit, she continued to swell and her arms and legs burst and started leaking fluid and she died. She did not improve at all on treatment those last months.' (Bereavement interview family carer, Patient 1)*

> *'When he left home to go to hospital in that last week he was weak but not so much but the swelling had started again, but he could walk a bit. But when he was re-admitted he became too weak that he never got off his bed at all. His legs and all his joints were weak and he said his lower body was paralysed. His blood pressure went down* and he was put on dopamine. *After a while the*

skin became dry and wrinkled I think because the water had come out, the eyes had turned yellow, he no longer looked good. He was in pain and he would tell them, the lower part of my body is weak, he could not even get off the bed.' (Bereavement interview family carer, Patient 8)

The second typology was a sudden and swift unexpected death in relatively stable patients and it came as a surprise to the family carers. In this typology of death participants developed acute events such as stroke, convulsions, probably arrhythmias etc. which led to death.

'I did not expect it when I brought him in the hospital that it will be his last day. He had been okay at home but had one problem, constipation and abdominal distension. So we came back on the 13th, the date we had been given for review. We hired a bodaboda (motor cycle) and when we got to the clinic I noticed he had become breathless and also when the doctor saw him he noticed that he was breathless. We were admitted to 3BE emergency ward) he later became restless and he fell down and started getting fits. I asked him what is the problem SSS can you recognise me? But his response was poor.' (Bereavement interview family carer, Patient 3)

'*She was discharged in a good condition but one day at home she suddenly felt a lot of palpitations, then she started coughing and vomiting blood. Initially it was light blood but then she started coughing out clots. I was preparing to bring her back to the hospital for review but she died that day at home, everything happened so quickly.'* (*Bereavement interview family carer, Patient 19)*

5.3.2 Place of death

Though family carers spoke of how they would prefer to care for their patients at home rather than in hospital, particularly if they also had family and other things to attend to in their homes, the majority of the deaths for participants in this study occurred in hospital with only three at home.

'The problem is that I cannot be in hospital with her I have children and I live on the islands when I come to Kampala I have to spend extra on rent. If she is admitted there will be no one to be with her in hospital because my other sister also has to stay at home and look after her children.' (Carer patient 1, phone interview 1 month before patient died)

Factors that influenced the place of death were:

Having information on the prognosis

Some participants and families, who knew that the situation was irreversible and knew that their patient was dying, opted to stay at home at the end-of-life. Those who did not understand that the patient was at the end-of-life still expected more

interventions and brought the patients to hospital. Patients were also brought to hospital when they had experienced acute events that had led to a worsening state.

> *'We wanted to take her to Nnn hospital but the last time we went to the hospital they had told us there was nothing much they would do. She also did not want to go to hospital anymore; she said she was tired of getting injections (Bereavement interview family carer, Patient 1)*

> *'Then we took her back to Mulago, she was much worse then, she could not even sit up, she needed to lean on something or someone, her legs were swollen by that time because her blood was not flowing well' (Bereavement interview family carer, Patient 16)*

How rapidly symptoms progressed during dying

For some patients death came rapidly and the families did not get the opportunity to bring them to hospital.

> *'He had been well but he suddenly became breathless and within a few hours he died before we could take him to hospital.' (Bereavement interview family carer, Patient 2)*

Patients' preference

Some patients opted to stay at home, particularly when they had conditions that would cause embarrassment in public, and when they realised they could not get a solution for them in hospital. For example, patient 1 was leaking fluid from her limbs and had been told there was nothing much that could be done in hospital.

> *'She died at home they had told us before in Abc hospital that there was nothing much they would do. Her arms and legs had burst and were leaking fluid and she did not want to go to hospital anymore'. (Bereavement interview family carer, Patient 1)*

5.3.3 *Causes of death*

In this study we were unable to get results of the autopsy to determine the definite causes of death, but in those who died in hospital the notes were reviewed and presumed causes of death included: electrolyte abnormalities such as hyponatremia and hypokalaemia, cardiovascular accidents and advanced structural heart disease leading to pump failure and renal failure. Given the description of the acute events in those who died at home, possible causes in those who had sudden death were arrhythmias, cardiogenic shock and pulmonary embolism.

The patients' dying experiences also revealed that they and their relatives were still treading in an unknown terrain and the themes that stood out as influencing their

dying experience included the expectations they and their families had which was largely determined by their limited literacy about this stage of their illness and their symptom experience.

5.4 Illness impact on the different dimensions of participants' lives

Living with HF affected different domains of the participants' lives and evoked various experiences in those domains throughout the illness journey. The areas affected included their understanding of their life and the illness, psychological, spiritual and social and quality of life domains.

5.4.1 Understanding of life and illness

The illness was not just experienced physically but participants had pondered on their diagnosis, the cause of the illness and prognosis and they had interpreted these in their context to be able to understand their illness. Participants' understanding evolved over the course of the illness and was influenced by the information they received from lay people and health professionals, their past and present experiences, their previous knowledge, their level of health literacy and their beliefs.

5.4.1.1 Understanding of the diagnosis

A major finding was the inaccuracy of understanding participants had of their diagnosis when compared to the information health professionals had recorded about them in their ward notes. Examples include that many participants reported that they were told their heart was surrounded by water yet they did not have a pericardial effusion.

> '*My daughter took me to Nna hospital and it was there that they found I had water in my abdomen and they sucked it out from this side,(points to the right). Then I got to know that my heart surrounded by water and the health care worker explained to me I had water in the abdomen.' (Patient 10 interview 1 - had no pericardial effusion)*

Participants also reported to have been told the following about their diagnosis: the heart was weak; the heart was swollen; problems with the blood vessels of the heart; but some of these were not consistent with what was in their notes.

> *'When I asked the person who was examining using the TV (ultra sound scan) of the heart on me what he had found he said we have found cracks and some of blood leaking on my heart, and he said if you take your medications they*

will go away.' (Patient 11 interview 1 –patient with hypertensive cardiomyopathy)

'I was then told the heart was tired and they told me that it was fever of the joints that led to the heart disease and the heart vessels are abnormal they were scarred and so blood does not flow.' (Patient 19 interview 1 -had rheumatic valve disease)

The lack of clarity may reflect the difficulty of translating and communicating the concept of HF to patients, especially the challenge of finding the appropriate words to use for HF and other heart diseases in the local languages. Statements such as '*the heart is surrounded by water'* appeared to be a commonly used lay expression for HF, used by other patients who had conditions such as pericardial effusions. The similarities in presenting symptomology regardless of the aetiology could explain how this lay diagnosis had become so popular. Patients feeling bloated and seeing swelling made assumptions that it was water that was causing this. Use of a similar phrase by health professionals to explain the difficulty in breathing associated with pulmonary oedema may have also contributed to its common usage.

5.4.1.2. Understanding of the cause

Most participants had reflected upon the possible aetiology of their illness, which was not always congruent with medical views, but it was what was intelligible to them. Their understanding was influenced by information from other lay people or health care workers. Illness was attributed to:

A diet with a lot of salt;

'The person on radio said if you add raw salt to food this will cause water to accumulate around your heart. Looking back when they said this I realized I ate a lot of raw salt long ago, when I was pregnant I would eat crystals of raw salt … it was my fault.' (Patient 1, Interview 1)

Doing manual work without rest;

'I think working too much, I used to work a lot I grew up in the village and therefore I had to dig, such things, may be being in the sun for the whole day was one of those things which caused it. I am not sure really.'
(Patient 14, Interview 1)

Comorbidities such as hypertension and HIV;

'The pressure went up so high and hit my heart and my kidneys and destroyed them, the lungs are destroyed because the heart is not working well the liver is also in trouble.' (Patient 20, Interview 1)

'But in my observation I think in all this is HIV. I think it is HIV that is causing the suffering; I may want to get an excuse that it is the heart but I think it is HIV… I think that HIV manifested as heart disease because sometimes it hides somewhere. Even the doctors tell me the heart is not really bad ….on the medical form they always write HIV. They often ask me where I get HIV care to make sure I am getting treatment for HIV.' (Patient 6, Interview 3)

Spiritual causes: Some participants believed that the illness was a test of their faith in God and what was happening had been predestined by God. Others believed satan as the cause of their illness and suffering. Those who also believed in traditional religions related the cause of illness to witch craft and evil charms.

'Nothing comes without His (Gods) knowledge, He knows, sometimes He brings it (illness) as a test, sometimes He tests us to see what your 'heart' is like.' (Patient 3, Interview 1)

'As you know in the village, people thought I had been bewitched, I even tried and went to a witch doctor.' (Patient 13, Interview 1)

A complication of childbirth as the baby moved through the womb;

'The illness started with delivery of the child I have told you, I had problems with delivery,when the baby was turning in my womb he kicked my heart, I felt bad during the delivery I felt chest heaviness in labour and told the midwife to come and check because I felt the child had pushed my heart but she ignored me and she just continued sleeping. When I was hospitalized sometime after the doctor asked me if someone had ever hit me on the heart and I said no but then I remembered what happened during delivery …the baby had kicked me on the heart.' (Patient 17, Interview 1)

Worrying a lot and a past history of being battered as a child;

'In my view, I think what caused it was too much worry in the past. What I remember is that there was something that happened to me in that year when I was pregnant in 2009.That incidence brought me a lot of worry. .. In my view going through that crying every night I remember I had lots of problems and now this was on top of the others I felt that my heart was heavy with sadness, so I think looking back that this might have been the cause.' (Patient 5, Interview 1)

'I even thought to myself this illness came because I was beaten a lot as child, I might have been beaten in a bad spot.' (Patient 12, Interview 1)

5.4.1.3. Understanding of the prognosis

There were various understandings of the prognosis of the illness. Many wrongly thought they were going to be cured.

> *'As usual I expect them to cure the problem.' (Patient 8, Interview 1)*

Others knew it was a chronic illness and would not get cured but expected a normal life span.

> '*I expect to improve, not to get cured,…..this illness has come in my old age , so this will be with me until I die, because there is no illness you get in your old age and expect that it will go away.' (Patient 6 interview 1, 50 year old with illness for 3 years)*

Others referred to death implicitly or directly.

> *'I am worried but I am just grateful that all my children are grown. The last one is in senior 4 at least he can stand on his own if anything happens.' (Patient 3, Interview 2)*

The culture could also have influenced the way they referred to the prognosis because it is usually taboo to talk about death as it is thought if you talk about it you invite it and one is expected to be optimistic.

5.4.2 The impact of the illness on the participants' psychological experience

Living with HF evoked psychological symptoms and issues throughout the illness journey and participants responded by employing psychological means in an attempt to cope with the illness.

5.4.2.1 Psychological symptoms and issues

The common psychological symptoms experienced were anxiety, sadness, anger, emotional pain and depression. Causes of worry and anxiety included: fear of dying;

> *'I was so worried that I was going to die.' (Patient 2, Interview 1)*

An uncertain future for them and their families;

> *'I feel sad sometimes, it should not come but what really brings it is when I think of my children, because they are so young.' (Patient 5, Interview 1)*

Being unable to work and losing jobs;

> *'It worries me because I buy the drugs myself because I work for my survival and buy the drugs, so I am so sad because I lost my job. (tears rolling down*

face) I do not know where I am going to get the medications.' (Patient 12, Interview 1)

Worry about the pain that could come as their illness progressed;

'The pain and suffering one goes through is what scares me most.' (Patient 7, Interview 1)

Often these causes of anxiety led to sadness as they realised that what they had feared was becoming a reality in the course of the illness. Participants also sometimes felt despair or sometimes were resigned to situations that they could not solve.

'We the poor people we shall just die… the medicines are expensive and most of our life is in the hospital, everything is expensive can we survive in this Uganda?' (Patient 6, Interview 3)

Participants anticipated being rejected and being a burden to others and this influenced their behaviour among their relations, leading to self-stigma, self-isolation and feeling ashamed of their new identity because of being unable to fit into cultural norms and values. All these aggravated the emotional pain.

'In our culture in our tribe your niece is treated like an in-law I should not be with her here but I have nowhere to live now. So I am at my in-laws' I should not even be near her husband and I should not shake hands with her but because I had nowhere to live, I am here.' (Patient 13, Interview 3 at home)

'You feel isolated you are not among friends and sometimes you isolate yourself so that you think about your problems because you feel there is no future, also you feel bad being that illness is what people know about you it is what defines you all the time you are Mr. illness,you feel abandoned.' (Patient 20, Interview 1)

The results from the APCA African POS in the table below show the prevalence of worry among the participants over the illness course and how often participants shared their problems with others. Worry tended to be worse in the first and last interviews and the rate at which participants shared their problems decreased over the illness course. The information from the APCA African POS in table 9 below helped to show trends of psychological symptoms over time which were not obvious from the in-depth interviews.

Table 9: Prevalence of worry among the participants over the illness course

Symptom	1st interview N=21 Symptom Prevalence n(%)	1st interview N=21 Prevalence of severe Symptoms (score ≥3) n(%)	2nd interview N=13 Symptom prevalence n(%)	2nd interview N=13 Prevalence of severe Symptoms (score ≥3) n(%)	3rd interview N=6 Symptom Prevalence n(%)	3rd interview N=6 Prevalence of severe Symptoms (score ≥3) n(%)
Worry	16(76)	15(71)	9(69)	7(54)	5(86)	4 (71)
Share with others	15(71)	N/A	11(85)	N/A	3(50)	N/A

N/A Not applicable

5.4.2.2 Coping with the illness

Participants dealt with their psychological symptoms and the suffering associated with the illness in different ways to help them live and cope in spite of the illness. Coping was a major theme in the illness experience. Different coping mechanisms were adopted shaped by their personality, culture and belief systems and the prevailing social context. Hope was central to coping and most mechanisms fostered hope. Sources of hope which facilitated coping included: faith in God and surrendering to Him and meditating on scripture which addressed concerns similar to theirs;

> *'I put all strength and trust in God because I would not have managed on my own strength because there is a lot of pain in this illness. There at times when it comes and you think I am not going to see the next day but because you believe you find yourself alive the next day if it was not for that ahaa, there is a lot of pain.' (Patient 20, Interview 1)*

> *'I am strong but it is just that God has not allowed my cure yet but I am hopeful that I will get better. I am not worried God knows my future my faith supports me. I left it in God's hands.' (Patient 1, Interview 2)*

Having a caring family, friends and community and feeling recognised as a person;

> *'My mother, she would counsel me, and others when they would visit me, they would give me some money to support me , so I felt that at least people still*

think about me I still have my people who support me so I counselled myself to be strong' (Patient 20, Interview 1)

Strength in numbers: realizing that they were not alone with their situation and comparing themselves with others in worse situations;

'I get my strength from others, because everyone is ill, it is not one person's suffering, it is just when your time comes.' (Patient 16, Interview 1)

'What strengthens me is that when you come to hospital you find many others in the same condition and you think let me take courage, we are many, I am not in this alone it is not for one person.'(Patient 17, Interview 1)

Sharing their problems with friends;

'For me where I stay, there are other people so sometimes I talk to them .. you know when you are among people, you forget most of the pain.' (Patient 4, Interview 1)

Practicing an attitude of gratitude;

'I know that a person cannot live without ill health especially at an age like mine. I am even thankful, what if I had cancer? What if I had diabetes mellitus those very bad diseases, but heart disease can allow me to work for myself , I can look after myself, I am thankful because whenever I feel I am getting worse I can come immediately to the hospital.' (Patient 6, Interview 1)

Listening to inspiring stories of those who had been through similar situations and triumphed from the Bible;

'I read and meditate on the psalms and the book of Job and read how Job suffered ..yes how he got ill , when you read this you realise that this has happened to other people before in the past and you get encouraged that you can pray to God and he can hear and answer your prayers.. I also read Ezekiel and it also comforts me, I read the Bible most of the time when I feel sad and discouraged I read one of these and then I feel my heart is stronger and get more courage to live on and I say God you know everything and I surrender it to you.' (Patient 5, Interview 1)

Other coping mechanisms which did not foster hope included acting stoically, avoidance, being destructed, letting go, denial of their situation , bargaining, accepting the inevitable and planning to move on.

'The most important thing is you have to forget your suffering, avoid thinking about it all the time that is why I told you I go for walks and do this and that I don't think about it. One cannot live without having ill health, it is so hard. You either have tooth ache, pain in ears , eyes or something, many things are on our body the lungs , so you find yourself that even you God has thrown to you one of them…so, struggle with that because God helps those who help themselves.' (Patient 6, Interview 1)

'It is a must you have to be strong in this illness.' (Patient 18, Interview 1)

'I used to worry but when I did my heart beat fast and I was not feeling well so I have let go.' (Patient 17, Interview 1)

'I stopped worrying, when my second daughter died, .. I am old anyway, why should I worry…. you know you have to let go. If you are helpless and poor even if you worry you just waste your time, will you go to your doctor and ask him for money? They may not have money as well. What gives me strength is because I have food at home, it gives me strength.' (Patient 11, Interview 1)

Those whose hope and coping were based on factors that depended on improved function became disappointed as they lost function with time, and had to find new sources of hope, such as having gratitude for their achievements. Participant 3 started off with denial in the first interview, his wife said they had been told he would not be cured but he said:

'I hope for cure not just improvement.' (Patient 3, Interview 1)

On the second interview when he was re-hospitalised his perspective had changed and showed he could not see a long life ahead of him but had another source of hope, he said:

'I am worried but I am just grateful that all my children are grown. The last one is in senior 4 at least he can stand on his own.'(Patient 3, Interview 2)

Those who coped by being stoic sustained it only if their performance status was good enough to allow them carry out activities of daily living. Those whose hope was based on faith tended to sustain their hope. On the second interview when participant 5 (whose coping was based on her faith) was very ill she still said:

'God cares and he has supported me throughout.' (Patient 5, Interview 2)

Also on the third interview when she continued to be worse:

'It is all God's mercy and if it was not we would not be alive.'(Patient 5, Interview 3).

Coping developed over time and those whose diagnosis had been recently made felt they had not been able to cope yet. '

I am not strong yet because I have a lot of questions on the illness as I told you before.' (Patient 8, Interview 1, had lived with illness for 3 months)

5.4.3 The impact of the illness on participants' spiritual experience

The illness induced different spiritual experiences in the patients and these were probably influenced by their previous religious and cultural beliefs and how their community perceived their illness when facing the unknown. Participants expressed spiritual pain and spiritual growth.

5.4.3.1 Spiritual pain

Participants experienced and described spiritual pain as follows:

Feeling valueless and rejected by God;

> '*For me I think God got tired of us, you feel of less value*, y*ou even reach the extent of admiring a crawling baby.' (Patient 4, Interview 1)*

Feelings of guilt for their past behaviour;

> *'Looking back when they said this I realised I ate a lot of raw salt long ago, when I was pregnant everything I would eat I had to add salt, tomatoes everything, when they said it over the radio I realized God has no fault, He did this to me intentionally because it was my fault.' (Patient 1, Interview 1)*

> *'Everything has a cause, and for me long time ago in my youth I smoked cigarettes, so whenever I tell people about my heart disease they always remind me of my past and the smoking. I feel that there is a lot of fun and enjoyment in life but choose those which will be helpful to you don't use harmful substances in your life.' (Patient 3, Interview 1)*

Results from the APCA African POS in table 10, give a broader view of the spiritual experience of the patients by revealing that many people (86%) reported having less peace than they had before the illness on the first interview and of 48% of all people at the first interview, rated their peace as being very low or having no peace at all. Peace was not mentioned in the in-depth interviews and therefore the APCA African POS added value by eliciting this concern that the patients had not spontaneously mentioned. Although all participants felt that their life was of less value than before the illness, only a few patients (10%,8% and17% rated their life value as being very low during the first, second and third serial interviews respectively.

Table 10: Prevalence of markers of spiritual well-being among participants over the illness course

Variable	1st interview N=21 Prevalence of problem n(%)	1st interview N=21 Prevalence of severe problem (score ≥3) n(%)	2nd interview N=13 Prevalance of problem n(%)	2nd Interview N=13 Prevalence of severe Problem (score≥3) n(%)	3rd interview N=6 Prevalence of the problem n(%)	3rd interview N=6 Prevalence of severe problem (score≥3) n(%)
Reduced Peace	18 (86)	10(48)	9(69)	1(8)	5(83)	1(17)
Life-less worthwhile	15(71)	2 (10)	13(100)	1(8)	2(33)	1(17)

5.4.3.2 Spiritual growth

Though there was spiritual pain, participants also described the time of illness as one of spiritual growth. Illness gave participants time for appraisal of their lives and for self-discovery. Despite the suffering associated with it, some participants reported developing some positive things or strengths, and growth through suffering, which included: having patience;

> *'I have learned that when you are ill you have to be patient, it is all God's plan and if He decides you can get better.' (Patient 19, Interview 2)*

Becoming more courageous and developing a stronger faith;

> *'I have learned that one has to take courage (be strong) because it is not one person's problem, it is for all, be patient with the situation whatever God has brought you have to go with it.' (Patient 16, Interview 1)*

Illness helped them to identify those who really loved and cared for them, and this may explain the peace they felt and how they rated their value for their lives.

> *'What this has taught me is that wherever there is a bad thing there is also a good thing. We know that illness is a very bad if one gets it and no one wishes another illness but it helps you identify who really loves you and who does not because in illness if someone remembers you then they really care for you. Because not everyone feels bad for you, some are happy others feel relieved*

you are out of their space. It gives you a lesson among your people who you should know is for you.' (Patient 20, Interview 1)

5.4.4 Effect of illness on participants' social life

Illness affected participants' lives especially in their socialisation and relationships. Some relationships were severed through isolation, rejection and stigma and others strengthened. The effect of the illness on the participants' social lives reflected the patients' and their communities values, beliefs, and culture, how patients coped with the illness and how the community responded to an illness they did not know about or understand due to low levels of health literacy.

5.4.4.1 Facing rejection, stigma and isolation

Participants faced stigma from family, friends and employers. Some female spouses were rejected and isolated by their male spouses because they were unable to meet their spouses' expectations and their roles in the family. Normal spouses faced pressure from the community to leave those who were ill.

'When I had just got married I became sick and my husband got tired of looking after me so I went back to my mother.' (Patient 19, Interview 1)

'His (the husband) friends and his relatives, they said she has no value take her back to her parents she is going to die.' (Patient 5, Interview 1)

'I was married but it was this illness that took me away from the marriage….my husband, he felt I could not satisfy his and the family's needs so I went back to my parents, I cannot even do any work.' (Patient 17, Interview 1)

This may reflect the values and norms of the cultural setting where women are obliged to meet certain roles and failure to do so, renders them of no importance in the household. In this setting men are not expected to adopt the caring role when their spouse is ill.

Participants also described how they were rejected by their employers because they were less productive than other healthy employees.

'On my last admission to hospital I had to leave work, so this time when he (the employer) heard I was in hospital he told my father, let her not return here. Let her get another job because I am always away from work.'(Patient 12, Interview 1)

Participants were also rejected and isolated in their communities because of beliefs that their illness was contagious or because they associated their illness to HIV.

'We do not relate well with neighbours because they think the illness will spread to them and catch them and yes even their children, they tell their children not to come near you. C; yes even sometime back I used to rent for her away from the village but women started complaining she is going to make us catch her disease yet we have children so the landlord told her to leave. Even in the village they say she is going to spread the disease to them.' (Patient 18 and her Carer Interview 1)

'Don't you know people? When you get HIV they say do not go to her home don't get close to her, that happens.' (Patient 6, Interview 1)

'People around me have started gossiping and wondering if this is really heart disease they say it is probably not heart disease, I think he must have jumped over some witch craft. They say a young man cannot get such disease as the heart disease. He has never been ill before, heart disease cannot progress that quickly.' (Patient 8, Interview 1)

With the progressive loss of function participants became isolated from social activities and groups because they had no ability and means of getting to them or because of the unbearable conditions there and unsuitable diet for their condition.

'For the last one year I have not been able to go (to social functions) and I cannot even go to church because of my legs. They are weak.' (Patient 1, Interview 1)

'Those parties with loud booming music, my heart feels like it is going to burst, I cannot go so it is difficult to go to some social events especially for people I am not very close to because there are things I cannot eat because of the illness.' (Patient 10, Interview 1)

5.4.4.2 Strengthened relationships

For some participants good came out of the illness, and some reported strengthened relationships during the illness and being well cared for and supported by their families and friends. Some described how their extended family members helped to support with their care and there was community spirit from members of the same faith.

'When I got very ill when my baby was younger one of my friends in church took him to her home and cared for him. And washed him slept with him and was like with a mum to him.' (Patient 5, Interview 1)

'My children strengthen me, they really care for me. Friends also come and visit me, and some even give me some money some 5000, others 10,000.' (Patient 9, Interview 1)

Participants felt they had a role in strengthening these relationships by behaving according to the expected norms in the community. This involved having an attitude

of stoicism in the face of illness to avoid early dependence and cultivating good relationships with neighbours.

> '*If I am unwell and have problems at night my neighbours come and help me, (coughs) I have not put the blame for my illness on my neighbours and I shall not do it. I tell my children that if I used to say wrong things and tell lies about my neighbours no one would be coming to our home by now.' (Patient 1, interview 1)*

> *'I try to encourage myself in my heart, I tell myself, even if I am feeling this way let me cover it up and I try to walk.' (Patient 8, Interview 1)*

Strengthened relationships were mostly observed between parents and children, regardless of who was the patient, probably because of the expectation that parents are obliged to look after their children and vice-versa and therefore care was not interpreted as a burden, but a duty. Neighbours and friends were very sympathetic to their friends and offered financial and family support to the families.

5.4.5 Quality of life within the illness experience

Understanding what participants interpret as a good quality of life or general well-being is important if care is to be tailored to the needs of those who are living with incurable illnesses. The phrases '*a good day'* and '*a bad day'* were used to explore perceptions of good and poor quality of life, as there is no simple translation of this concept within the Luganda language used in the interviews. Participants reported that a good day or a good sense of well-being was when they were able to do the following: have a good sleep at night; eat; participate in their roles such as child care; do private self-care; work for a living; get rid of more troublesome symptoms such as palpitations; engage socially; get some money and get food; as well as having tolerable symptoms. A bad day constituted the opposite of the above. QoL for many was related to the level of functioning, although for some it was just having basic needs such as food.

> *'If I do not sleep well and can't take myself to the toilet, when I have to use a bucket for a toilet. It makes me sad that I have to tell my young daughter to help me to a bucket for my toilet. When that happens that is a bad day, I feel bad. However if I can be able to walk and go outside and do simple chores such as washing the dishes…one time I felt strong, washed the dishes cleaned the house, organized the house I felt very happy, it was a good day.' (Patient 5, Interview 1)*

'There are days when you wake up in the morning feel not too bad, when the heart is not beating alot and when I feel a little stronger I feel better at least that day is good just like the past 2 days have been.' (Patient 19, Interview 1)

'On a good day even my friends find me conversing and they bring tea and I take it and bring food and I eat a bit and they say she has had a good day today.' (Patient 1, Interview 1)

'A good day is if I can peel the food and I tell the children to put it on fire. A bad day is *the day I fail to do anything and they find me asleep when they come from school.' (Patient 4, Interview 1)*

Summary

This chapter explored patients' experiences of being diagnosed with, treated for, living and dying with HF in Uganda. The major themes that emerged from the patients' experiences included: experiencing symptoms and change in performance status; health illiteracy; influence of culture and beliefs on the illness experience; health system challenges; impact of illness on the daily lives of patients; adaptation and coping with illness and its treatment, poverty and other social challenges, influenced by an overarching theme of living in the unknown.

Experiencing symptoms and change in performance status: symptoms from both the cardiovascular and other systems dominated the lives of those with advanced HF and they greatly limited patients' performance status which mirrored the course of their illness. Symptoms were not considered as due to the disease until they were considered significant as determined mostly by the community where patients lived and when this happened care was sought. Most symptom scores did not change even whilst on treatment, reflecting the advanced end-stage disease present in most patients.

Health illiteracy: this research identified that there was limited or no health literacy among the population interviewed and the general public and this led to a delay in recognition of illness, delay in seeking care, and in insufficient self-care. It also influenced patients' choice of where to seek care, their use of medications, their understanding of illness and its expectations from treatment.

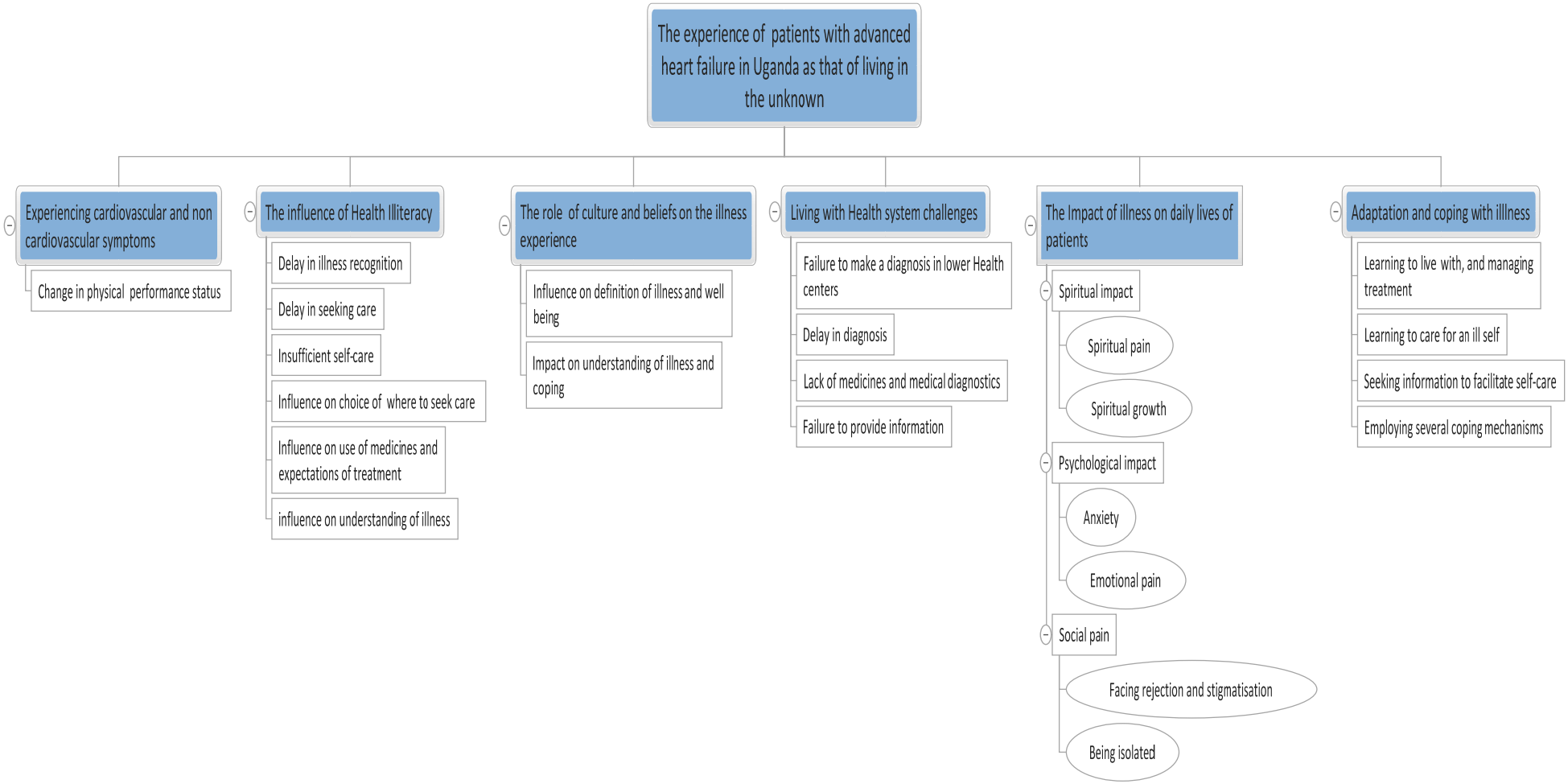
The culture and lay knowledge and beliefs of the population influenced their illness experience by influencing the definition of illness. For example, in this culture where

work is essential to the community for survival, illness was when one was unable to work and if one was able to work they were not ill. Patients' faith beliefs were a strong source of hope and coping with illness, but sometimes hindered adherence to treatment in those who believed in a faith cure. Beliefs in witchcraft as a source of illness led to seeking care from witch doctors. There was a lot of interaction between health illiteracy and relating illness to witchcraft. Due to the limited health literacy, lay knowledge from patients' families, friends, the media and peer patients which was often not medically informed or very limited in medical information, but was rich in local beliefs and was relied upon in order to make health related decisions.
Health system challenges: the patients' experiences also showed that there were several health system failure issues including failure to make a diagnosis in lower health centres, delays in making a diagnosis once patients presented to the health system, lack of medication in hospitals and a failure of health workers to provide required information on the illness to the patients.

Impact of illness on the lives of the sufferers: The illness had consequences on the patients' social, psychological and spiritual domains. It impacted them psychologically leading to a life interspersed with anxiety, worry, sadness, and emotional pain, and patients had to find ways to try and find a psychological balance again. Socially, some relationships were strained and others strengthened, participants faced rejection, isolation and stigmatisation. Spiritually, some participants expressed spiritual pain and others spiritual growth. The psychosocial and spiritual impact of illness was interrelated with the culture and beliefs of the participants and lack of health literacy.
Adapting to and coping with a life with illness: most of the patients' experiences revealed that living with HF was a life of continuous change and patients had to continuously adjust to it. This involved learning to live with treatment, managing treatment, learning to care for an ill self and seeking out information to facilitate self-care and employing several coping mechanisms so as to be able to live despite the illness.
The overarching theme in the illness experience seemed to be that of getting into and learning to live in and with the unknown. This was observed when patients experienced symptoms but could not relate them to disease and when they failed to recognise illness, how patients responded to the diagnosis, how they found managing

of their treatment onerous, how they attempted to understand the illness and adapt to the illness and their psychological, social and spiritual responses as well as the community responses to the patients by stigmatising the patients. Living in the unknown was largely influenced by health illiteracy.

Figure 4: Summary of the themes from the patients' experiences of living with and dying of advanced heart failure in Uganda



CHAPTER SIX

6.0 Introduction

This chapter will present the analysis of the patients' needs and concerns over the course of their illness, and the factors influencing changes in needs, and concerns over this course. It will address study's objective 2.

Objective2. To map the pattern of patients' needs and concerns over the course of their illness and the factors influencing the changes

The participants' needs and concerns over the course of their illness and factors influencing changes in needs.

There were similar broad categories of multidimensional needs and concerns (physical, information, psychological, social and spiritual) over the course of the illness, however some needs and concerns tended to be more prominent at particular stages in the illness journey, and others spanned the whole illness trajectory. The different categories of need and concerns over the illness journey and factors influencing the changes will be discussed below.

6.1 Need for treatment of physical symptoms and for a cure

Participants expressed the need for having treatment to control uncomfortable symptoms that impaired their function in order to return to function and work, and to prevent death.

> *'I thought, how can I go home with no medicine? I cried a lot before the health workers because I knew my pain and I knew that if I go back without the treatment…… I was worried that I would die, because I had a lot of pain.' (Patient 2, Interview 1)*

> 'That *is why I went there (to hospital) because as a human when you are breathless you know death is near.' (Patient 16, Interview 1)*

> *'We need to be well enough to carry out our daily work.' (Patient 3, Interview 1)*

Many participants hoped for, and wanted, a cure for their illness when they went to health care services for treatment.

'I would not aim for just improvement but when I am still sick, I want to be okay and cured to do my work.' (Patient 20, Interview 1)

6.1.1 Factors that influenced changes in physical needs and concerns

Physical needs and expectations to meet physical needs, tended to change over the course of the illness and factors which influenced the changes in these needs included:

Duration of the illness

Those who had had the illness for longer (usually more than a year), regardless of age, tended to focus more on the need to feel healthy than to be cured, than those with a recent diagnosis. As the illness progressed, and they went through a series of recurrences of symptoms despite the treatment, they appreciated that cure may not be possible and their needs for complete control or cure of symptoms changed. They now hoped for times or days they would be free of those symptoms or when the symptoms would be less intense and they would be 'normal' and functional, so as to be able to do those things that were very important to them.

'Most people tell us that the heart disease does not cure but at least it can be controlled and someone feels better…. we need medicine to help us. We hope that he improves and goes back to normal life because he has workers, his expertise. For us at this age of 50 we know that anyway we do not have a long life to go we shall not have 100 years ahead and so we know we can die…. If it does not get better can someone at least have a normal life?'(Carer Patient 3, Interview 1 – had had illness for one and half years)

'But most of us know we will not get cured already, if something is not just a simple fever of malaria, do you expect it will cure? Does one expect a heart disease or kidneys disease to cure? I know I will not get cured I take medicines to feel better and to feel healthy.' (Patient 12, Interview 1 - 18 years old with 3 history years of illness)

Age

Younger patients expected, and wanted, a cure rather than just improvement of wellbeing, but older people were more accepting of just improvement in their wellbeing. This is probably because for younger people the illness had interrupted their biography and planned future, and they were desperate to get back to normal. They were often more frustrated than older people when treatment did not bring about improvement.

'As usual I expect them to cure the problem. I would like to know , … what treatment do I need which one should I emphasize ,….how long will it take me

to get better because I was in school now I cannot and my friends are going ahead.' (Patient 8, Interview 1 - 21 years old with illness for 3 months)

'I expect to improve, not to get cured,…..this illness has come in my old age , so this will be with me until I die, because there is no illness you get in your old age and expect that it will go away.' (Patient 6, Interview 1 - 50 year old with illness for 3 years)

Having information about the condition

Those who had more information about their condition tended to focus more on the alleviation of symptoms than complete resolution of their symptoms through a cure, than those who did not know the gravity of their problem.

'I expect the medicines to cool (improve) my condition, but not to cure it, I do not expect a cure. But what really discourages me is that even when I swallow them I do not feel better. I cannot walk from say here to outside this ward.' I was told the ultimate thing is to take me for an operation and replace the valves.' (Patient 14, Interview 1, - 18 years old with illness for 3 months)

Faith in a higher being

Some participant's needs and expectations were influenced by their very optimistic attitude, influenced by the faith they had in God and their hope in a miracle.

'For me my focus is on being cured, that is what I ask God every day to get cured because he has taken me through a lot and I feel the heart problem is so small before Him'. *(Patient 20, Interview 1 - had illness for 6 months)*

6.2 Information needs

Information needs were ranked amongst the highest needs in the study, highlighting the patients trying to grapple with the unknown. Throughout the course of the illness, participants needed information from the health professionals on different issues, and their information needs changed over time.

6.2.1 Need for information on their illness symptoms, causes, prognosis and test results

Throughout the course of the illness but particularly in the diagnosis stage, participants expressed a need for information on the cause and meaning of their symptoms, the pathology, the cause of the illness and its prognosis, probably to help them come to terms and cope with the illness.

'I want to know what the cause of the illness is, how does it start? Does it come from what you eat or do and does it cure or not?' (Patient 18 and her carer, Interview 1)

'I would like to know what caused this heart disease, what is there in the heart and the water that is always accumulating in the abdomen where does it come from?' (Patient 21, Interview 1)

They also wanted an explanation of the results from the tests and examinations done to answer the above concerns.

'They have done several scans but have not explained to us the results they did not explain to me the echo too because the person who explained only explained the first echo. I would like to know, what *the problem is.' (Patient 8, Interview 1)*

'Sometimes after examining us you cannot understand what is written about the scan but they do not explain to you anything they just go away .But you are the doctor and I have come to you, help me understand at least give the information to the patient if you cannot give it to the family carer but it is important to know what is going on. But the reason I came to you is because I want to know.' (Patient 18 and Carer Interview 1)

As participants lived with the illness they came up with beliefs of the causes of their illness and wanted to check and compare their lay beliefs against the information from the health professionals.

'I would like to know why the heart got this water around it what was the cause. Is it doing heavy work, is it due to any work I did or was it because we were in a war zone for a long time? Is it because in that period we ate bad food? We would just eat anything in Luwero.' (Patient 1, Interview 1)

'I want to know, is the heart seated in water or is it the blood vessels that are blocked or is it a hole in the heart?' (Patient 5, Interview 1)

It was also interesting to find that participants wanted information so that they could explain their illness to their community. This may be because in the Ugandan context unexplained and unknown illness is likely to be stigmatised as due to a curse, or to be labelled as HIV which is also stigmatised.

'Even in our community among friends, when you are telling them about the illness they ask what is the problem really, what do the doctors say, and you have nothing to say.'(Patient 5 interview 1)

The majority of participants wanted to know their diagnosis and prognosis even if it was not good, a few did not want to know, and a few had a dual narrative on this. This is contrary to what most health professionals in Uganda think, as they think that

patients in the Ugandan setting and culture do not want to know their prognosis, especially if it is poor, and it is one of the reasons they give for not revealing diagnoses to patients. Patients needed information to be given in a sensitive manner and to maintain hope.

> *'If you do not tell me because you think it will scare me, it will not stop hurting me, so I do not want to lie to me it is better to know if I can take care of myself then I do it.' (Carer Patient 18, Interview1)*

> *'I don't want to know more about the illness because I might be scared. Let me live with the knowledge I have.' (Patient 6, Interview 1)*

> *'Either way you get worried because if I want to know more about the heart it may cause me to worry. On the other hand I would also want to know because something may develop and if I have heard of it before it can help.' (Patient 7, Interview 1)*

> *'We know the heart does not cure but one should not tell us in a way to make us lose all hope. If it does not get better but one is well enough to go back to work and almost normal that gives hope. Yes, one should not take away all hope.' (Carer Patient 3, Interview 1)*

During treatment, participants also wanted to be updated on their disease progress and the effect of treatment.

> *'I would like to know where my life stands,…because so far I have not been able to walk around, I would like to know how strong I am.' (Patient 10, Interview 1)*

A lack of information left participants and their carers not prepared for death, they did not know how to manage the terminal phase of the illness leading to a lot of suffering during this period. There was only one participant who referred to a conversation they had with her health professional about her condition not being curable.

> *'I did not expect it when I brought him in the hospital that it will be his last day.' (Carer Patient 3, Bereavement Interview)*

6.2.2 Need for information on names, the role of medicines and the importance of adherence to the medicines

During the treatment stage, participants wanted to know the names of the medicines they were taking. 16 out of 21 participants did not know the names of the medicines they were taking, and this probably affected their continuity of treatment. Most of them did not keep their medical documents well and therefore they often had their medications changed when they were re-hospitalised in the emergency room, or when

they went to other hospitals, because they had no record of the treatments and did not memorise the names of the medicines.

> *'We do not know the names of the medicines. I will not tell a lie we do not know, even we do not have the medical documents. I took the documents to her home just in case she gets worse when I am away because I do not live with her and she did not come with them.' (Carer Patient 18, Interview 1)*

Participants expressed a need to understand the role of the treatments in the pathology they thought they had in their hearts, and also how the treatments would influence the outcome, in order to be motivated to adhere to the treatment. When participants were not sure of the role of medicines and these medicines were expensive, they would opt to buy cheaper ones.

> *'I was supposed to get some injections but they did not give them to me. It was very expensive when I went to buy it at a private pharmacy, I went with 20,000 shillings but they told they cost 30,000 per injection and I had to get 5 of them, I just gave up and did not buy them… I do not know what those injections were for.' (Patient 12, Interview 1)*

> *'I would like to know, what treatment I need which one I should emphasise. Explain the disease, the cause, how the treatment will help and how it works. That will be clear and the patient will be more convinced and will also put in personal effort.But some of the tablets are not labelled with names and sometimes my attendant gives the tablets without their packets. Sometimes I also ask him what is that for and he says they wrote it. You believe blindly that the doctor prescribed it but have no confidence that what you are taking will help you. If then you swallow and do not improve you become discouraged.' (Patient 8, Interview 1)*

Some participants wanted to know why the treatments given were not giving the results that they expected from them and if the medications were responsible for some other symptoms they were experiencing.

> *'I also wonder why I sometimes swallow the medication and do not pass out water because I am very committed to taking the medicines and I want to take them so that I can pass out the water.' (Patient 5, Interview 1)*

> *'Sometimes when I swallow them I cannot eat, so sometimes I think they may be the cause and sometimes I think because I did not reveal that I have stomach ulcers I might be getting some medications I am not meant to get, because I hear people with ulcers should not take some medications.' (Patient 3, Interview 1)*

Some participants just needed some clarity on the medications because they had a lot of confusing lay information on what treatment is more useful, and needed the doctors help to discern the right treatment and what to concentrate on.

> *'Most people you told would say let us try our local herbs stop taking western medicine, I have my local healer who can help. Everyone had a herbalist they knew and different medicines. All this confused me. I started thinking should I leave this medicine I got in the hospital and I go home and get herbal medicines or should I stay in hospital where they told me the heart is swollen. I would just keep quiet but I was also waiting for a doctor to help me discern. But the problem is that you go to a doctor and he cannot give you information to discern as I told you before.' (Patient 8, Interview 1)*

6.2.3 Need for information on self-care

Most participants, 17 out of 21, wanted information on what they could do to improve their well-being and survival. They needed information on what to avoid in their illness, the recommended diet, water intake, how much physical work to engage in and other lifestyle modifications they needed to make. They wanted to be involved in their care by getting information on their condition.

> *I would like to know everything so that I can avoid those which may cause more harm, I need to know the do's and don'ts.' (Patient 12, Interview 1)*

> *'But in general I have not got a health worker to explain to me what should be eaten and what not to be eaten, because even for the salt it was the other doctor who first worked on us here but then there came another female doctor who said it is okay she can eat a little but we have never been taught on what to eat.' (Patient 18, Interview 1)*

6.2.4 Need for information on presence of other co-morbidities

A few participants needed clarity on whether they may have other co-morbidities, this could have resulted from the worsening of their clinical condition along with having many unexplained blood tests, which led them to think there may be something else wrong with them and to anticipate other co-morbidities. HIV was commonly thought about, probably because it is believed in many Uganda communities that every unexplained disease is HIV and blood tests are often associated with HIV tests. They thought information was being concealed from them and wanted to know if they had other co-morbidities.

> *'If I have 'the disease' (HIV) let them tell me the truth.*
> *I: why do you think that you have 'the disease'?*
> *P: well you never know.. my blood is checked whenever I come in but they do not tell me the results. I would also like to know if I have any other illness*

they should let me know if it pressure (high blood pressure) , I need to know everything.' (Patient 13, Interview 1)

'Yes, I would like to know if I have 'the disease' (HIV), they have taken off my blood twice and it was negative and they have now taken off another time.'
I; did the doctors say they were going to check for it?
P; I do not know but they said they were going to check my blood and I thought it was for 'the disease.' (Patient 17, Interview 1)

6.3 Psychological needs and concerns

There were a lot of psychological needs as participants started a new life in the unknown, and when they faced loss due to the illness. These included a need for reassurance, a need for counselling about treatments, a need to have a sense of completion, a need for empathy and a need to maintain hope.

6.3.1 Need for reassurance

The diagnosis process was a time of much psychological strain for many patients and they needed reassurance and psychological support during this process. They felt a lot of uncertainty and anxiety during the prolonged period of having tests, and especially when the tests did not yield any answers and because this was a condition unknown to them.

'..and they found that I had no HIV. I cried before the health professional I thought they were lying and told him to tell me the truth because I was in a desperate situation similar to what you see now as I look now, I was very thin. I told him to tell me the truth so that I can get treatment and be able to bring up my children because it is only me who cares for them I am their only future. So he told me I cannot tell you what I have not seen but advised me to go to a bigger hospital.' (Patient 5, Interview 1)

During treatment when the patient did not improve, or when they got worse, they also became anxious and expressed the need for reassurance.

'But if in the morning the next day, if there is no improvement when receiving treatment, you even get worse because you feel worse, you think of other things.
I: what things do you think about?
P: That my end has come because if you are not getting better.' (Patient 10, Interview 1)

The need for reassurance was emphasised by some patients who preferred some health professionals who were considered to communicate better, over those who did not, as expressed in this quote:

'We female patients prefer the men to check us because when you complain to a man he will encourage you to be patient and persevere and will counsel you, yet he is a man. But women to women, it is bad yet we are the ones who know pain, we have experienced pain of child birth, but a man has not felt yet he usually comforts you and encourages you.' (Patient 16, Interview 1)

6.3.2 Need for psychological preparation and counselling for treatments

Participants also were anxious about some invasive procedures, such as chest drains, that were being performed, along with some treatments with negative connotations in the community, such as oxygen and having surgery, and they needed to be mentally prepared for these procedures.

'One day they wanted to take me to have oxygen and I thought… yiiii. How will they put my heart on that machine and I still continue to be alive….. to be sincere I was scared of it.' (Patient 9, Interview 1)

'Also as you know they removed water from my abdomen and I was told that if they start sucking out the water in your abdomen then it will continue coming back all the time and you have to come back here all the time which worried me.' (Patient 5, Interview 1)

'When they checked, they could not find the problem and I was told you are going to be operated in theatre but I was worried because I did not know why I was going to have surgery' (Patient 1, Interview 1)

6.3.3 Need for attaining life goals and having a sense of completion

Participants also conveyed the importance of achieving their life goals and were saddened when these dreams were threatened because of their loss of function.

'Yes, I am very sad because all the time I have spent in school and now I just stop there without achieving what I wanted.' (Patient 14, Interview 1)

'My biggest worry is that I have not completed my house…..
C: yes it even affects his life so much and well-being because he worries; because it is not good to get sick at another person's house.'
(Patient 3 and Carer Interview 1)

6.3.4 Need for empathy

Some participants felt they were not getting enough attention when the health professionals talked to them and felt they needed them to validate their needs and give them more attention.

'The other thing is that they should also put themselves (the health professionals) in the position of the patient especially when they are talking to them. Let them take time to know from the patient what they need.' (Patient 8, Interview 1)

6.4 Spiritual needs

6.4.1 Need to maintain hope

Participants also wanted their health professionals to give them hope, despite all that was going on, and not to destroy it.

> *'You get strength after counselling, if a health worker comes and says you will get better, the health worker and patient carer should not let the patient lose hope. Tell them that you are at this stage of the illness when they come back for review. But some health workers when you come back to hospital tell you 'we are tired of you'. This is very discouraging.' (Patient 7and Carer, Interview 1)*

6.4.2 Need to find the meaning of their illness

Participants struggled with what was happening to them and wanted to know if there was a reason for it, and often sought existential or spiritual answers. The illness to some was interpreted as a test from God and they needed to understand how to pass the test.

> *'I say to myself, I am an unfortunate person already because my mother abandoned me, why would such a grave illness come to my life, an illness which will not get better! I sometimes ask myself why God brought me such a serious illness like this.' (Patient 2, Interview 1)*

> *'It is a test and you have to go through it.… In my religion it is said that every test must have a reason for its occurrence and must have an answer to it. So this is what scares me most because, whenever there is a test and you have no answer you must be scared that you have failed. So if an illness comes and you don't know the cause you just know that it will continue to get worse because you do not know what the cause is.' (Patient 8, Interview 1)*

6.4.3 Need to re-establish a sense of purpose

As some participants began to appreciate that their dreams and anticipated desired future may never come to pass, they felt their life purpose lost. They wondered what the future had for them and what their purpose was without their dreams. They needed to re-establish a sense of purpose.

> *'I have no parents I am already disadvantaged and if I do not go to school because of the disease , how will I just sit at my aunt's home, how will I survive in this our Uganda. It is necessary for one to go to school. I sometimes cry because of this.' (Patient 2, Interview 1)*

6.4.4 Need to be valued and treated with respect and dignity

Some participants articulated the need for being treated humanely, they were angry when treated badly because they were in a helpless state. They were struggling for a sense of self -worth. Feeling valued and wanted in their vulnerable state led to hope.

> *'When I get people to look after me my heart feels strong and I say God I know illness has to come but when I feel wanted , I am consoled. For example when I tell my daughter she encourages me and says mama please we need you, she sends me some money if she has it.' (Patient 21, Interview 1)*

> *'I want the health workers to come just as you have come here you have sat with me and asked me what my problems are, and I need them to check me and give medicine. I feel at peace in that way and will feel that my doctor has cared for me, she has understood that I am a person.' (Patient 5, Interview 1)*

> *'I need someone to come and talk and counsel me; do not shout at me, I feel happy and strong. You do not have to give me anything but treat me well as a human so that I do not get angry or worried .But if you treat me badly, yet you are my relative I get hurt.' (Patient 13, Interview 1)*

6.4.5 Need for spiritual support

The need for spiritual support was also identified in this study as participants experienced spiritual pain which manifested as periods of questioning their faith in God and His plans, feeling abandoned and rejected by God, wondering if God was punishing them and feeling valueless. Many participants wondered why this had happened to them and why the timing of the disease. These questions were common amongst those who had a past of suffering and were hoping for a better future, which they now saw as fading before them.

> *'So I said to God after all I have been through is this You choose to pay me with? Is this the time You decide to give me this? You have seen wherever I have been.' (Patient 20, Interview 1)*

> *'Sometimes I keep quiet and think about my life and worry and I ask God what I did to deserve this, to be pricked all the time with injections.' (Patient 21, Interview 1)*

> *'I wanted to stay at the church for some days and nights to pray so as to….but I did not spend enough time there because I failed to get a carer who would be with me in that place.' (Patient 18, Interview2)*

6.4.6 Need for spiritual satisfaction and healing

Some participants felt the need to get better spiritual satisfaction and healing and began to question the adequacy of their previous spiritual beliefs. This led to

searching for where they could get these spiritual needs met.

> *'I became a born again Christian because of this illness because He says 'whoever is overburdened let them come to me'. So when I felt overburdened I said to myself if He says 'I am the way the Truth and life and whoever knows this will be set free' so I decided to be saved. I was a catholic but there is no anointment there, there they say as it was in the beginning now and forever.' (Patient 20, Interview 1)*

6.5 Social needs and concerns during the illness

Needs and concerns related to participants' social life were very prominent in the illness journey, particularly as participants lived longer with the illness and as they lost function. These included concerns of multiple losses, life disruption, lack of finances and concern for their families. Participants' main social needs were for practical support, being able to participate in their family roles, need for companionship, need for independency and the need to have control.

6.5.1 The concern of having multiple losses, life disruption and the need for a predictable future

The participants' social lives were dominated by loss as a result of the illness. They were very concerned about the losses which made the future look bleak. At the core of all loss was the loss of function that triggered off a sequence of other losses. Loss of function led to loss of work and income, loss of social roles, loss of school, loss of dreams and a promising future which made them feel out of control of the situation. For most participants the most significant loss was that of loss of income generating work or loss of a future that would lead to income generating work. This was probably very significant because of the already existing social context of poverty and deprivation, and work is the only way out of this situation.

> *'At the time the illness started I was working looking for money to further advance my studies…. I wanted to do civil engineering and it involves manual work, this really discourages me.' (Patient 14, Interview 1)*

> *'This illness has taken away my ability to work for a living.' (Patient 1, Interview 1)*

6.5.2 The concern of being dependent and the need for having control

Having some degree of control of their situation was very important for some participants and they were saddened by being so dependent. Some participants even

preferred to have HIV because it gave its sufferers time to plan and hence a sense of control, and others tried to avoid being invalid by having timely review of their illness

> '*Ever since I got ill I have never been able to plan anything in my life. But at least some diseases you can plan and work and save money to support you when you are weaker. You envy those with HIV because it will not come today and make you dependent tomorrow, except if you want to. You can get treatment get better and have some time to plan. There are things like the dress I am wearing you want as a normal person to be able to buy it yourself, but if one has to give you their clothes all the time it does not feel good. You even fail to have some basic necessities at home and also you get to the extent of begging for 500 shillings. There should be a limit.'*
> *(Patient 13, Interview 1)*

> *'That is where I started my struggle…..I felt like I had become an invalid, disabled, a disability which is not physical or not seen. I would think I am a man and I am expected to do some work to sustain myself. I should not be like this. That would also make me cry.' (Patient 20, Interview 1)*

> *'Whenever I feel I am getting worse I can come immediately to the hospital, I don't wait to become like porridge, I hurry and come back to hospital. I come early and get help and do not wait to become porridge; who would carry me? I would be bothering/ burdening people close to me.' (Patient 6, Interview1)*

6.5.3 The concern of poverty and the need for money

Poverty leading to financial crises was a prominent social problem in the participants' lives and participants were very concerned about it because they were unable to meet their basic needs such as getting food, the required medicines and transport to hospital for medical care. Financial crises resulted from loss of jobs leading to loss of income and this was superimposed on an already existing state of poverty. These financial crises were exacerbated by the high costs of treatment and tests, inconsistent supply of medicines which had to be purchased on a private basis, transport costs and costs of self-care and costs of care for the family. By the time of death, patients' family carers had used up most of their resources to buy medications. Those who had opted to go for private care so that they could get more attention had to revert to general care.

> *'But this illness, I no longer work, but when I was working I was well off but since this illness started it is a problem so I stopped working …If I only I can get food, I am starving because you see since morning I bought my daughter and her child breakfast but I could not eat when there was a child so I gave it to her and I just took tea, but I would like to eat but the financial situation does not allow me.' (Patient 21, Interview 1)*

'Now we have spent all the money, we are here now here (general ward) we started down (private ward) but then we could not afford the bills there.' (Carer Patient 9, Interview 3)

'My biggest problem is poverty because all the money I get goes to buying medicines and so all the time you are poor.' (Patient 20, Interview 1)

6.5.4 Concern about other losses and changes in their lives

Some participants were concerned about the loss of their body image and other losses which were a consequence of their illness, such as a loss of property and homes and death of family members who got ill while the patient was hospitalised.

'This illness changed me a lot and shrunk me I was very good looking and fat just like that lady you see (she points to a lady in the room who is just as she described) although I was short but this illness has shrunk me I am always struggling with it.' (Patient 21, Interview 1)

'Even one of my children died at one year and four months, and she died at the time I was admitted in the hospital, she got sick when I was away.' (Patient 4, Interview 1)

'I had bought some things a lot of things home property to develop our home but whenever you go back home after a hospital admission you find that there are even no plates and when you ask what happened they tell you they broke or times they are not sure what happened to them and even when a visitor comes to your home you find you have no plate to give him/ her food and you feel so discouraged because you are not progressing socially you are like one who has just come from the village who does not live in the city.' (Patient 5, Interview 1)

6.5.5 Need for practical help

As participants neared the end of their lives they became extremely weak and most of them became dependent requiring support from their carers in practical areas and all areas of their activities of daily living and sanitation. The carers had to leave their jobs and devote most of their time to caring for them. These needs for practical help were mainly voiced by their carers.

'*I even left my job and stayed at home to take care of him to ensure that he takes his medication on time and that he gets all the care he needed.' (Carer Patient 3, Bereavement Interview)*

'I had also been in the village. I had just gone to the village on Sunday and they called me on Monday it was about 1pm may be towards 2 pm and they told me I should come back because he was in hospital and the brother caring for him would not be able to manage him alone. His condition was not so good and he could easily fall of his bed. By the time I came from the village

my brother could not manage to care for him alone he needed 2 people then.' (Carer Patient 8, Bereavement Interview)

6.5.6 Concerns about their families

Participants were concerned about their families' welfare and future because their illness had disrupted their family carers' lives, who had to leave school or their jobs to care for them as they became more dependent. Some participants were concerned that their children were left unattended and unprovided for when parents were ill and hospitalised and some children had to take on the role of the parent in their families when the parents were very ill.

'At the moment they (her children) are alone at my mother's house with my younger siblings.' (Patient 19, Interview 1)

'Even my brother is now here he had to go to school but all his programs are disrupted because he had to miss this term to care for me and we are not sure what next because we do not know how long we are going to be in this situation.' (*Patient 8, Interview 1)*

Due to financial reasons children had to leave school, there was no food to eat in homes, and family assets were sold in order to buy treatment.

'This child taking care of me now stopped going to school because I was sick, She had just started her Primary 7 and done one term but I could not afford her fees.' (Patient 13, Interview 1)

6.5.7 Need to fulfill family and social roles

Participants longed to participate in their family roles especially when they had children who were young. They felt they needed to care for their children.

'*That is my family, they are young. I cannot even wash for them or cook for them that is how it is with this disease.' (she says it almost crying) (Patient 5, Interview 2 at home)*

'I would like to be able to take part in the care of my children, until they grow up, it is what worries me. I would like to live longer and be strong enough to care for them so that I am even able to buy them some clothes.' (Patient 19, Interview 1)

6.5.8 Need to be able to work

Participants tried to avoid being invalid, probably as a community expectation, and to maintain their position and role in society. As physical performance declined they began to take on less strenuous work and started pacing their activities with rest until

such a point that they were unable to do any work at all. They tried to modify their environment to make it suitable to their disability and their carers helped in this by bringing all they needed to enable them do some work and reduce on their dependence.

> *'I cannot even climb up because as a carpenter usually you climb up and hold up the roof alone but now I cannot manage to do that. I just stand there and tell people what to do now as a supervisor.' (Patient 3, Interview 1)*

> *'I cannot do the little work I used to do but may be sometimes I try to work and ask the children to bring the food nearby and I can peel it then I can cook it. They have to bring all that I need to cook near to me.' (Patient 4, Interview 3)*

6.5.9 Need for companionship

Some participants were concerned about the lack of companionship and support whilst they were at home, as they lived alone.

> *'Yes I am worried I do not have someone to live* with*….but I live here alone no one even to make me a cup of tea.' (Patient 18, Interview 2)*

Summary

This chapter investigated the pattern of patients' needs and concerns over the course of their illness and the factors influencing the changes in needs.

Participants' needs and concerns were found to fall into five broad categories i.e. physical, information, psychological, social and spiritual needs. All these needs were underpinned by the overarching need to return to an integrated self and life that had been disrupted by the illness. The main theme in the physical needs was the need to return to a functioning self and this was implicitly expressed as the need for a cure and the need for the relief of symptoms. This need tended to change from the unrealistic need of complete cure and return to completely normal function, to a more realistic expectation of the best possible performance state when patients had a longer experience of the illness, if they had information on the illness and also in those with old age.

Participants' interviews revealed that the need for information was a very important unmet need. Patients required information on the cause of the illness, the diagnosis, explanation of results of the tests done, the role of the different medications and their

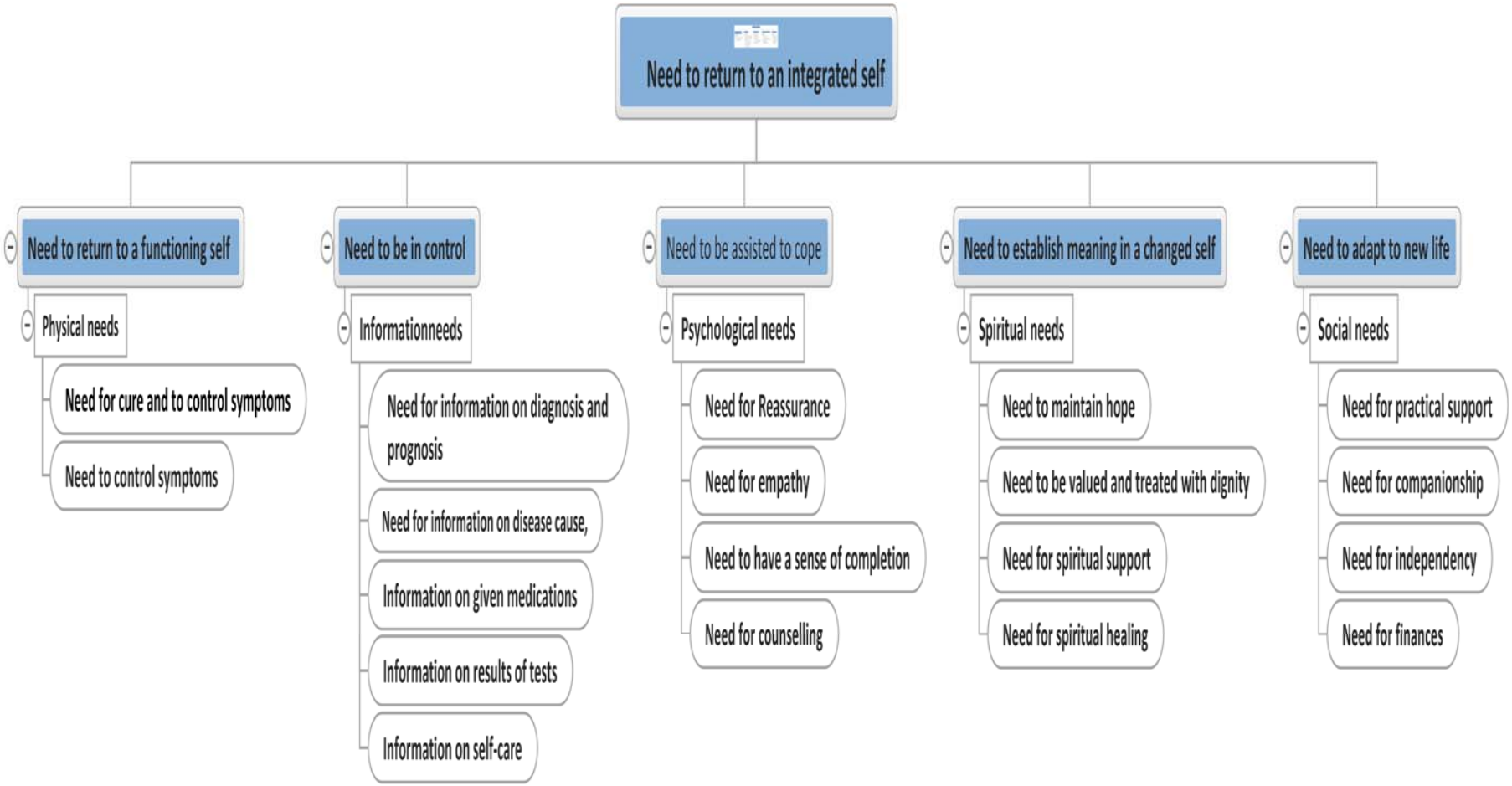
side-effects, progress on treatment, self- care and the prognosis of the illness. The main theme underpinning all information needs was the need to be in control. Lay narratives, myths and beliefs from lay people played a major role in driving patients to seek information from health professionals.

The core need underpinning all psychological needs was the need to be assisted to cope and adapt to a life with illness, and therefore participants expressed the need for reassurance, the need for counselling, the need for empathy and the need to have a sense of completion. The core need underpinning spiritual needs was the need to find meaning in a life that had been changed and shaken up by illness and when living in the unknown. This led to various spiritual needs expressed as the need to find the meaning of the illness, the need to maintain hope, the need to re-establish a sense of purpose, the need to be valued, the need to be treated humanely with respect, the need for spiritual support and the need for spiritual satisfaction and healing.

Social needs and concerns stemmed from multiple losses that led to a disrupted life. The centre of all loss was the loss of function that led to other losses, and therefore the core need underpinning the social needs was the need to adapt to the new circumstances. Therefore their social needs included the need for practical support, to be able to participate in their family roles, the need for companionship, the need for independence, the need for finances and the need to have control.

The following figure (Figure 5), shows patients needs as classified into the five sub-categories physical, psychological, social, information and spiritual. Each of these subcategories of need are driven by a higher need (need to return to functioning self, need to be in control, the need to cope, the need to re- establish meaning in a changed self and need to adapt to new life). The overarching category of need was the need to return to an integrated self.

Figure 5: Summary of patients' needs



CHAPTER SEVEN

7.0 Introduction

This chapter will present the analysis on patients' perceptions of the services available to meet their multidimensional needs, and how they matched with need. It will address study objective 3 and part of study objective 5.

Objective 3.To map services available to patients and how they matched with need

Objective 5. To capture from both patients and professionals perspectives on what would constitute better care and how this can be achieved

Participants tended to describe the services available by referring to the health care facilities and health care workers.

7.1 Patients' perceptions of the health care facilities

Participants described receiving services from in-patient settings, out-patient hospital settings and in private clinics. They had different perspectives about these settings.

Hospitalisation

Participants' descriptions of health services were dominated with narratives of hospitalisation and re-hospitalisation. The number of re-hospitalisations from the time of diagnosis to the end of the study period ranged from 1 to 6 for the different participants. Intervals between hospitalisations became shorter as the disease course progressed. Their perceptions of hospitalisation were both positive and negative.

Positive perceptions and experiences of hospitalisation

Many participants held in-patient hospital care in high regard and considered it as a source of life and well-being and although there were challenges at home arising during hospitalisation because of their absence from home, they did not regret being hospitalised.

> *'Being in hospital is life, well if I do not come to hospital because I am worried about my property at home, I will still leave them if I die, but life is priceless, your things could get stolen when you are in hospital but you can later get money and buy them but if you lose life it is different.'*
> *(Patient 10, Interview 1)*

One participant was impressed that the care she received exceeded her expectations of the national referral hospital, which was often portrayed negatively in the media and by the public.

> *'Ever since I came here for this admission I have been impressed, I did not get what I expected, whatever the public says about this hospital. I am happy with what I have got so far. In 3BE, they welcomed us well, even here, I found what I did not expect to find. They say that there are no health care workers in Mulago and unless you pay a health care worker in Mulago they will not see you, but that is not true, I have found out that they are available and are many. But it has been very good here if they could continue with that trend here it will be good.'(Patient 11, Interview 1)*

Negative perceptions and challenges of hospitalisation

Although the majority of participants appreciated the importance of being hospitalised, some participants had had negative experiences and challenges with previous hospitalisation. Most of these negative experiences reflected health system problems and others were problems at home arising because of the patients' absence. These negative perceptions and experiences included:

Having to face and be aware of the reality of dying everyday

This was because many deaths happened on the cardiac wards and these caused a lot of anxiety for patients who had similar illnesses, as expressed by this patient:

> *'It is hard, sometimes you are not ready for it then they tell you are going to be admitted to hospital also while on the ward you may be sleeping next to a person and the next thing you know they are worse and then they are taking them away to the mortuary, you may fail to sleep again because you think I have the same disease as him.' (Patient 20 interview 1)*

Lack of privacy and living in fear of contracting new diseases

Participants felt that there was limited privacy in hospitals and feared contracting diseases from other patients. This was because the wards were overcrowded and some patients did not observe good sanitary measures because they were too weak to go to the toilets and therefore passed urine or opened their bowels using buckets or basins on their beds. This waste sometimes was not quickly taken away for disposal, especially if the family carers were away. In public hospitals, because of the large number of patients, there is very little space between beds just to allow a health professional to go through and examine the patients and therefore patients are very

close together. Also there are no curtains to screen one patient from the next one so whatever goes on in a nearby bed will affect the neighbour and also a neighbour will always see one dressing or when having a bed bath which is so intrusive for many people

> *'No one wants to be here, we also fear to contract new diseases and the ward is crowded,some people use buckets on their beds as toilets, we also feel uncomfortable in the hospital. I do not like being hospitalized myself and I plead not to be admitted but you find yourself back.' (Patient 4, Interview 1)*

Lack of order in the services

Some participants described a lack of coordination, especially in the emergency services, where health care workers were unable to prioritise them for care when they were very ill and kept on referring them from one health professional to another. They seemed to imply that some health professionals wanted to get rid of the responsibility of caring for very ill patients and would send them on to other colleagues who also sent them to another.

> *'It is terrible we are being chased from one area of the ward to another, one says I do not see the very ill and when you go to another they tell you why don't you go in the emergency ward and in the emergency ward they want you to go elsewhere so we really do not know where to go.'*
> *(Patient 6, Interview 2)*

Disruptions in their homes

Some participants had to leave their homes and young children without anyone to attend to them and also lost their home property while away from home. There were also more costs associated with being hospitalised.

> *I: 'How does coming to hospital affect you?*
> *P; mainly I struggle with transport costs and leaving the children at home.'*
> *(Patient 19, Interview 1)*

Disruption to family carers' lives

Family carers explained how they had to leave work because they had to attend to their relatives who were hospitalised and this resulted in loss of income, yet there was great need for money in the family in order to cater for the patients' needs.

> *'Well I work from home but if I have to be in hospital I worry because then where will I get the money to care for her if I am not working.' (Carer Patient 18, Interview 1)*

'The time I have spent here in hospital, I cannot work yet we have to buy the medicines and the patient may need some drinks but you are not able to provide for them. You need money for investigations the X-ray, echo of the heart, such things.' (Carer Patient 7, Interview1)

The out -patient hospital services

The outpatient hospital clinics were often described as very congested, disorganised and with long queues.

'We suffer a lot in the out-patients clinic waiting in the queue even if you came very early or not there is no difference.' (Patient 5, Interview 1)

'The waiting is very long in the out-patients' clinic and sometimes you wait but at the end you still leave without medicines, sometimes you come and they tell you there are no doctors today and they give you back your medical documents and you have to go back home without treatment.'
(Patient 12, Interview 1)

Some patients had to come and stay in the emergency ward (as lodgers, without being hospitalised officially) the night before the date of their outpatient clinic so that they were the first in the queue in the outpatients clinic in the morning to ensure that they were reviewed in the clinic.

'If I am to come to the clinic for review, we wake up very early, because at 7.30 am they start collecting our cards in the clinic. I usually come and sleep in 3BE (the emergency ward) the night before and at 3 a.m I go to the clinic and put my card at the reception.' (Patient 6, Interview 1)

Other hospitals and private clinics

Most participants sought initial care for their HF in private clinics and sometimes lower level hospitals because they were accessible and there was less waiting. When they did not improve in those private clinics or if a diagnosis could not be made, they were referred to a referral hospital by the health professionals in that unit. Sometimes the patients and their carers made the decision to go to the national referral hospital. After leaving these clinics they lost faith in lower hospitals and small private clinics. Patients felt that the private clinics were driven by the desire to get money from the patients but they were not competent.

'She took me to a nearby clinic…They took off my blood and were not even giving us the receipts and then they told me you are okay, you have no problem, imagine he said I was alright and he had already taken our money.' (Patient 20, Interview 1)

'It would be good if all patients all come to Mulago first because they go to so many other places and they give them wrong medications.'
(Patient 11, Interview 1)

When participants went to lower level hospitals they were frustrated by the lack of medicines in these centers and failure to attend to their needs. Often health professionals in those centers confessed that HF was only treated in the national referral hospital. Lower health centres and hospitals are not training centres for health professionals, and therefore health professionals in these centres miss the chances of updating their knowledge through teaching. Although the medical council in Uganda requires a medical officer to have a minimum of fifty continuous professional development (CPD) hours per year to renew their practicing license, medical officers tend to cover all ward areas and all disciplines (medicine, paediatrics, obstetrics and surgery) because of a shortage of health care workers, and may get their CPD hours in another discipline such as surgery and not medicine.

'You see there are nearby hospitals but once you mention that you have heart disease in those hospitals they tell you rush to Mulago that is where those who treat heart disease are. If it was not for them talking like that, 'rush to Mulago that is where those who treat heart disease are' I would not come here so often because it is far and expensive.' (Patient 16, Interview 1)

7.2 Patients' perceptions of health care workers

Based on their experiences, patients had formed various opinions of their health care workers. The term health care worker is used here as opposed to health professionals because participants' descriptions included everyone who worked in hospital and was in uniform. In Uganda everyone who works in hospital and is in uniform is referred to by patients as 'musawo' (which can be translated as health care worker) and includes the medical, nursing, allied medical staff and support staff such as cleaners, and those who prepare and serve food etc.

Most participants had no problems with their health care workers and found them to be caring.

'*I have not got any health care worker who gave me a hard time. All of them if I ask them anything they answer me in a kind way.' (Patient 14, Interview 1)*

They appreciated that their health care workers did their best in the circumstances they worked in.

'*We only have one doctor in the clinic these days. But he works hard, he does not just touch you but he takes care to ask you in detail how you feel and leaves you when you are satisfied. But the doctor is also human. I have no problem with them they do care for me.' (Patient 10, Interview 1)*

'Well the health professionals also get tired because we are many patients.' (Patient 17, Interview 1)

Some even perceived their health professionals as protective of them by not telling them the truth about their illness to keep them from worrying: this may be a common view that the community holds of health professionals.

'When he said I had heart failure I asked him am I going to die? But he said no, I thought he was lying that he was trying to make me feel better.' (Patient 6 interview 1)

However some participants had had instances in which the health care workers actions and behaviour fell short of expectations. Some of these negative experiences included being insensitive in their communication and patients felt that health care workers did not consider the impact of their words on the patients.

'We were chased away from the hospital by the young doctor. He told us that heart disease does not cure and we should go to local clinics near our homes. He said save your money so that you can buy passion fruit juice instead of wasting it on transport, you should have heard him speak it was very hurtful.' (Patient 1, Interview 2 at home)

This patient said she had no problems with her health care workers when the first interview was done in hospital but when interviewed at home she had the different narrative above, and therefore the setting in which the interviews were conducted could have influenced the patient responses.

Some participants perceived their health care workers as rude and cruel because they had treated them so at the time they were very vulnerable.

'The female health care workers some are very rude and cruel. There was a woman who was registering me when I came in, every one complains about her, she is very rude. The situation is bad because I have been observing them.' (Patient 16, Interview 1)

Participants also sometimes doubted the competency of their health professionals, especially after they failed to give them a correct diagnosis or often when the health professionals told them they could not manage their condition and gave them

medicines which patients clearly knew were not meant for heart disease. This happened mostly in the lower health units.

> *'The health care workers who are in our district hospitals they will give us the same treatment they gave before we came here, they may just give you panadol, will they have helped you? It is better you come here.' (Patient 17, Interview 1)*

Some participants thought some health care workers displayed a negative attitude and lack of interest in their work.

> '*Well some health care workers seem not be interested in what they do.'*
> *I; what do you mean?*
> *Pt 20; 'They are not concerned about the patient, one may come and say where are the files and if you are not fast enough to get it they will walk away without giving you the medicine and then you have to follow them begging.' (Patient 20, Interview 1)*

> *'Sometimes you are lucky and find a very kind health care worker who really cares for you and sometimes you find a harsh one, who has no time for you. The other day I was sleeping here and was resting and the nurse came and got my file and told me to go and bathe. I was very weak, I could have collapsed, it hurt me. Sometimes in the outpatient clinic you may find a health professional who talks to you very well, asks you how you feel and asks you to come so they examine you. But there are those whose path you cannot cross. You cannot even start explaining about your illness they just ask you what?' (Patient 5, Interview 1)*

They also felt that the health professionals were always hurried and did not have time to listen and explain things to them, leaving them unsatisfied.

> *'But sometimes they are so much in a hurry that when they come they check quickly and they leave.' (Patient 8, Interview 1)*

7.3 Patients' perceptions of how available services met need

Patients' accounts revealed that the services available met some of their needs but some services were missing and therefore some needs were not met.

7.3.1 Patients' perceptions of how available services met or failed to meet physical needs

Most participants were able to have some symptom control soon after the diagnosis was made and the correct treatment initiated, and this often followed being referred to the national referral hospital.

'*This medicine, the water tablets helps me. If I was not taking it this swelling of the abdomen will bring me back to hospital without my willingness to come.' (Patient 1, Interview 1)*

However services did not meet the physical needs in most hospitals including the tertiary referral hospital. This was because of the health systems challenges described above in the health facilities. Patients complained of uncontrolled symptoms and these symptoms tended to be those outside the cardiovascular system.

'My biggest problem is the burning in my chest, the heart burn if only it can be treated.' (Patient 8, Interview 1)

'How can I get medicines for constipation, I asked the doctor but he did not give me any.' (Patient 3, Interview 1)

I also observed from the medications prescribed and from participants' interviews that participants received treatment mainly for their primary heart diagnosis and HF but very rarely for other non- cardiovascular symptoms such as pain, heart burn and constipation, which were causing significant distress for them and symptoms were not a focus for therapy but there was a tendency to treat the underlying problem. Non-cardiac symptoms were often unrecognised and untreated and even when mentioned by patients they tended to be overlooked.

'I have a lot of pain in my chest, like wounds when I eat, I do not know what it is but I need a doctor to check it out, it started when I was still in hospital and I told the doctor but he ignored it.' (Patient 5, Interview 2)

Reasons for unmet physical needs included:

Lack of medicines

Participants described having prescriptions for several medications, but only very few being available in hospital although government hospitals are meant to provide these medicines. They contended that the lack of medicines led to persistence of symptoms.

'*Yes they only gave me one type not even the water tablets were given to me, they were not available. At least if those tablets were there I would be a little better.' (Patient 6, Interview 2)*

'We have to buy some medications, ever since I came to the hospital I had not got any dose, not until I pleaded and had to buy the medicines but most times when we come to the clinic there are no medicines.' (Patient 5, Interview 1)

The lower hospitals were worse off than the referral hospital for availability of medicines, especially new medicines used for HF. This may be because the medicines may not be on their essential medicine list and also because the health professionals there may not make requisitions for them because they may lack new information on these new medicines which improve mortality in HF.

> *'When we go to those hospitals and the medicines we need are not there'. (Patient 13, Interview 1)*

Lack of diagnostic equipment

Participants also described a lack of diagnostic tests such as x-ray machines and echocardiography in lower hospitals, which led to delayed diagnosis with subsequent delay in the control of symptoms. Echocardiography machines were only available in the referral hospital, with a few available in private settings but these were unaffordable to most.

> *'They asked me for a chest X-ray at Nakaseke but the machine here was out of function, so they referred me to Lacho.' (Patient 5, Interview 1)*

Congested and overwhelmed services

Services were often very busy and poorly staffed and sometimes patients were turned away without treatment.

> *'There is a time when we came to the outpatients' clinic and she was really unwell, her legs were very swollen and they sent us to that place. You know after discharge we were told to come in the clinic on fourth floor and we came back the first time in the clinic and sat and waited and there were many patients waiting to see the doctor, and we were told the doctor sees only 5 patients and so we were told to go away without treatment. When we came back a second time we came early and the doctor saw us and asked us to bring the scan and x-rays that had been done - we had forgotten them at home, so we went back without treatment and so when we got home she was not able to wait for the appointment that had been given to her she was feeling bad the abdomen was very distended and it was not a day for the clinic that is why we went to the emergency ward. When we got there she was very ill but they just left us in the very long queue so I called my brother and when he came we decided to take her away from there to a private clinic which had a doctor.' (Carer Patient 18, Interview 1)*

7.3.2 Patients' perceptions of how available services met or failed to meet information needs

All participants had received some information about their illness verbally from their health professionals, most had got it at the time of diagnosis but this information was

insufficient for the patients and led to confusion.

> *'Also on the other ward they told me it was the heart was enlarged now they have told me it has water so I am no longer sure what the truth is.' (Patient 12, Interview 1)*

Sometimes the restricted use of salt was advised.

> '*The first doctor I saw on the first admission told me to stop taking salt and for some time I did not take it anymore but then I went back and then he told me to put in very little and completely avoid raw salt.' (Patient 10, Interview 1)*

However patients' needs for information ranked among the highest. Reasons why information needs were not met included: Lack of an organised system for giving information such as printed information. This may be partly because most of the patients are illiterate. There were also no dedicated organised sessions for providing information to patients verbally and yet clinics are usually crowded and there is not much time to give information in a medical consultation. One patient contrasted their situation to pregnant mothers who are routinely given verbal information in the clinics in Mulago as they wait to see the health professionals.

> *'We do not get any special information, we are not taught in the clinic , they do not tell you , only pregnant mothers are usually given information about their conditions in hospitals but not other diseases.' (Patient 16, Interview 1)*

Not only was information lacking for patients, but also for health professionals in the care system because a good and easily accessible health care record system was found to be lacking. Participants rarely kept their medical documents and this affected continuity of care when they were readmitted or when they went to another health facility. Medical records in Mulago are mainly on paper (plans to have electronic records are underway) and may take a while to be retrieved when someone is readmitted. Sometimes treatments which had been working well were changed when someone was hospitalised.

> *P: My medicines were changed when I came for the last admission and since then I got worse.*
> *I: didn't you give them your medical records?*
> *P: I could not find them, I think I lost them (patient 4 interview 2)*
> *Medicines have been changed from the emergency ward from the ones patient was taking (carvedilol, captopril, Lasix to nifedipine and lisinopril) probably because of lack of documents (Field notes for Patient 4, Interview 2)*

7.3.3 Patients' perceptions of how available services met or failed to meet their psychological needs

None of the patients reported receiving psychological support from the health professionals but patients felt the health professionals did not have time to address their psychological needs.

> *'The other thing is that they should also put themselves (the health professionals) in the position of the patient especially when they are talking to them. Let them take time to know from the patient what they need.' (Patient 8, Interview 1)*

Sometimes the health professionals caused psychological pain.

> '*What I see since I started to come here there are 3 to 4 issues which hurt me very much. The way female health workers treat us, they abuse us, when we are weak. For example there is one lady who cleans this place who told me that she will confiscate my basin if she finds it on the ward tomorrow, but what was I supposed to do they had chased my carer out of the ward, I was so weak, they chased my carer you remain helpless like a baby, that hurts me, but the lady was quarrelling a lot.' (Patient 16, Interview 1)*

Patients described psychological support being provided by their family carers and sometimes their communities, but did not mention any formal psychological support services in the hospital, but expressed a need for them as described in the chapter on needs.

> *'My children strengthen me, they really care for me. Friends also come and visit me.' (Patient 9, Interview 1)*

7.3.4 Patients' perception of how available services met or failed to meet their spiritual needs

Participants described their spiritual support as being offered by their relatives and friends in the community, and their faith community, but did not mention spiritual support from their health care workers. The participants or their families often initiated the provision of spiritual care by calling in people to pray with them. Spiritual care tended to be received through organised religions and traditional beliefs. Spiritual support was a source of strength and hope for the participants.

> *'I am strong but it is just that God has not allowed my cure yet but I am hopeful that I will get better. I am not worried God knows my future my faith supports me. I left it in God's hands. I pray with several people they come*

here those of my faith and even stay overnight, I even went to Bukalango (prayer place of healing in Uganda).' (Patient 1, Interview 2)

'The church is just nearby my home they come and pray with me.' (Patient 5, Interview 2)

'I have been living in the church where she prays and they were praying for me. There is a house where people stay who have come for prayers a pastor's house and I wanted to stay there to pray so as to….but I did not spend enough time there because I failed to get a carer who would be with me in that place so I had to come back here.' (Patient 18, Interview 2)

7.3.5 Participants' perceptions of how available services met or failed to meet their social needs

Participants seemed to be unaware of the presence of social work services in the hospital and did not talk about them. They referred to some health care workers who occasionally supported those who had social needs, but these were humane acts done randomly but not regular services. Most social needs which were mainly financial were unmet for the patients.

'They told me to go home but I had no money to take me home. So the health workers contributed money for me and gave it to him (the family carer) to transport me home.' (Patient 18, Interview 2)

Most social care and support was provided by the family carers, and the friends of the patients, and it came mainly in monetary form, as most patients needed money, but also in practical support.

'My husband tries his best, also friends help a lot, those who know me they say mama AA I have brought you 2000/= or 1000/= and you collect this and have some. Even people from church, and not from church, many people. I have many friends who help.' (Patient 5, Interview 1)

'Friends also come and visit me, and some even give me some money some 5,000, others 10,000.' (Patient 9, Interview 1)

Friends and relatives helped with caring for young children at home while patients were hospitalised.

'I: so who cares for your youngest who is 3 years old?
P: ever since I got sick my friend, God has been kind to me because he has no problem, people around help him. When I got very ill when he was younger, one of my friends in church took him to her home and cared for him and washed him slept with him and was like a mum to him.'(Patient 5, Interview 1)

7.4 Patients perceptions of what constitutes better care and how care could be improved

Patients' suggestions were centered on two main themes regarding what better care should be, i.e. improving the health care system and what they required from or expected of their health care workers.

7.4.1 Improving the health care system

Several suggestions were made on improving the health care system including:

Increasing the availability of medicines for heart failure

Participants felt this was one of the biggest problems that needed to be attended to in the health care system, because they had financial problems and could not afford to pay for their medications.

> *'The biggest problem is that sometimes the medicines they prescribe for us are expensive and they are not available in the hospital, in addition there are transport costs so the medicines should be more available especially the expensive ones, because sometimes they prescribe them and you have no money and yet probably they would be the ones to help you . You may have to go without it and the illness continues to worsen and it would be very good to get them from near by hospitals.' (Patient 14, Interview 1)*

> *'Let them give us more care such as caring for us, giving us the medicines, medicines should be free.' (Patient 9, Interview 1)*

Making tests and investigations more financially accessible

Participants and their family carers also felt that there was a need to make tests and investigations for HF patients in government hospitals more accessible because they were very expensive, yet very essential.

> *'What I would like is that when we come to hospital and they are to do like scans of the heart, they should at least reduce the costs of these investigations or not charge for them or at least to reduce the costs because we are told we need 50,000 shillings for one investigation and 80,000 for another, one may not have this amount of money at the time, if they could charge less.' (Carer Patient 7)*

Better coordination of care

Participants also argued for better organisation of care in order to ensure that everyone gets treatment when they come to a health facility. In Mulago Hospital the system is such that injectable medicines are given at a particular hour because of staff

shortages and if a patient is off their beds during that time because they are out for investigation/test, or if their carer is not around to give to the nurses the medicine they have bought, then they will miss that dose because the nurses may not be available at another hour or may be giving another service elsewhere. Therefore patients wanted a system that is patient friendly, not only staff friendly, in order to ensure that they get their medications.

> *'Sometimes you ask a nurse to give medicines and if you delay even a bit they go away and then they tell you we already gave medicines it is past time for injections and sometimes we the carers have been sent out of the ward when doctors are checking patients. So because of that my mother has missed her injections twice.' (Carer Patient 18 interview 1)*

Participants also wanted to have better coordinated care so that the correct order of arrival of patients to the clinic is considered in the clinics when reviewing them. They also wanted to reduce congestion in the clinics. Usually patients are given an appointment date in the clinic but are not given the time they should be seen but are worked on a first come first served basis. Some patients were disappointed because they came very early and left late, because some aggressive patients, who arrived late, found their way to the health professionals before them.

> *'However there are incidences which hurt us, such as seeing someone who came after you being seen first. That hurts if you come early and those who come late are seen before you and it needs to be improved.' (Patient 10, Interview 1)*

Also many times patients may return early because they are not given enough medicines. This makes the queues longer and sometimes patients may go home without being seen.

> 'Y*es the delay is real you may come early and at the end of the day you are turned away, or you may have to wait the whole day to have an investigation or to be seen, you even feel worse at the end of the day.'*
> *(Patient 20, Interview 1)*

Improving emergency services for HF patients

Participants thought that there were big challenges in the emergency care especially in the area of recognition and prioritising who needed care first and therefore some patients were not attended to quickly and died in the emergency services.

> *'Also we know this is a government hospital but sometimes you have a very sick person but they consider those with money and status first. Many people die in the emergency ward. They should improve these services and see the*

sickest first. The last time we came in the hospital she was very badly off but in those days if you did not know anyone in the hospital and you came with an ill person they would die right in-front of you when you are just looking at them.' (Carer Patient 18, Interview 1)

'They should quickly attend to the patients when they come because patients with HF can die very quickly. To quote an incident that happened when my daughter was admitted about 5-6 years ago, they brought a woman to one of the wards, it scared everyone who was admitted to the ward, they put her in bed and put her medicine besides her bed but did not come back to give it to her. But at about 1 pm her heart beating so fast and by morning she was dead, no health professional had even come back to check on her.' (Patient 11, Interview 1)

Reconsider criteria for discharge

Participants also felt that the main criterion being used for discharge on the ward was based on the length of stay on the ward, and yet that does not represent improvement. Sometimes the treatment is not available and is started several days into hospitalisation and they were therefore arguing for basing discharge on how long you have been on treatment.

'Sometimes they discharge us too early and tell us you will get better from home. But if you came yesterday and have not got any medications yet you may have spent a number of days on the ward but did not get any treatment so they may discharge you based on how long you have been on the ward. If they are to do that they should start the treatment immediately on admission so that someone improves.' (Patient 5 interview 1)

'Generally I think the health professionals when caring for people they should care and put in their heart and also follow up on what they are treating to find out how the treatment is helping or not but they rarely do that. Even usually they discharge patients before they are better and you see those discharged cannot even walk and they tell them to go and to come back worse.' (Carer Patient 16, Bereavement Interview)

Providing services for psychological support

Participants also thought one of the things that would improve care was to provide services for psychological support to help with the worry that they had.

'Counselling is needed, if a health professional comes and says you will get better, the health professional and carer should not let the patients lose hope,. Tell them that you are at this stage of the illness when they come back for review.' (Patient 7, Interview 1)

'We also need counselling and talking to me it would make me worry less.' (Patient 2, Interview 1)

Providing information services

This being one of the biggest needs it is not surprising that participants wanted services that could provide them with information on their condition as this patient explained:

> *'We need to be taught. We are so badly off in that area of information we have not been told at all, we have not been taught, may be others have but certainly not me.' (Patient 16, Interview 1)*

Views on home care services

None of the participants mentioned home-based care as a way of improving care but when they were asked their opinions on this as a way of improving care (because most of them had financial difficulties that prevented them from coming to hospital) there were mixed views. Some wanted it, although they did not express much enthusiasm about it

> *'That would be good, so that they come and see how you are progressing, I am not against that.' (Patient 10, Interview 1)*

> *'To treat you at home?....it would be good one can save on transport costs.' (Patient 14, Interview 1)*

Others felt it was too much to demand of the health professionals. From the interviews it was clear that patients' expectations of health professionals did not include home-based care.

> *'As a patient you cannot tell a health professional to come from Mulago Hospital and say go to Mbale in the mountains to come and see you at home.' (Patient 15, Interview 1)*

> *'That would be giving the health professionals a lot of work, it is too hard. Can you drive to my home in Luwero it is too much. The doctor studied, you cannot move the doctor. If it is the doctor who decides that we shall come every 4 months to review you then that would be okay. Doctors do whatever they can, they give you drugs for one and half months, here they care for your life and to save on transport costs they can even give you a date of review after 2-3 months. Some of our homes are in a poor state, the doctors might say no wonder this patient got ill. But when they see me in the hospital at least I look good.' (Patient 1, Interview 1)*

Some participants did not have the concept of home care in their minds and found it strange, and others felt they may not get full care if seen at home as all the medical equipment will be left in hospital and cannot be carried to individuals' homes, reflecting the low health literacy rates.

'One may like it to be seen at home but how about if one needs to have a scan or if they need injectable medicines and water in a drip?' (Carer Patient 7)

'Those who ask for homecare expect too much but as for me I would like to find the doctor in a place which has machines to check me.'
(Patient 6, Interview 1)

7.4.2 What patients required from their health care workers

There were two issues which stood out from patients' accounts on what they expected of their health professionals: improving their communication skills and relating with patients in a professional way.

Improving communication

This was a very common theme arising in more than two thirds of the participants with a range of areas of communication they thought needed improving.

Having empathy

Participants wanted their health care workers to be empathetic to their situation and really care about them and treat them as people, especially as they communicated to them to encourage them as expressed by these two patients:

'It depends on how one communicates. It is true some health care workers are rude, or tough, but this should be changed in the health professionals so that the one going to tell a patient about her illness should communicate in an acceptable manner. If you were to come and say how you are and how was the night I shall tell you the situation and ask me if I took my medicines and encourage the patient to take the medicines. Explain the dangers of not taking the drugs. In that way the patient is convinced that the health care worker cares about me and also wishes me well. And gets courage and he also learns what the problem is. I think that way of communication would be good. The other thing is that they should also put themselves in the shoes of the patient especially when they are talking to them.' (Patient 8, Interview 1)

'Just as you have come here you have sat with me and asked me what my problems are and you check me and give drugs. I feel at peace in that way and will feel that my doctor has cared for me, she has understood that I am a person.' (Patient 5, Interview 1)

Listening and being attentive to the needs of the patients

This was another aspect of communication that participants longed for. For one patient, this defined a good health care worker, who did not want to directly criticise health care workers but nevertheless described what she valued in a health care worker.

'I have not seen any bad health care workers in my opinion and they do examine me well. Yes. Even at kk hospital, they help me and care and treat; even here I have not had any problems. When you explain to the health care worker that it is here that hurts, they try hard to check that area. What would have caused me to complain would be if you told them your problem and they ignore it and if you told them where it hurts and one did not check, but if they examine a patient and think about the problem how this did come and how did that come that is enough.' (Patient 1, Interview 1)

Another patient also emphasised the need for health professionals to have the time to listen to what patients need.

'Let them (health professionals) take time to know from the patient what they need.' (Patient 8 interview 1)

Keeping hope alive

Participants explained that they valued communication that did not take away all their hope and was not all discouraging. They argued that even if the condition was not curable, health professionals should also give some positive messages in their communication and not only predict doom as expressed by the carer of this patient:

'We know the heart does not cure but one should not tell us in a way to make us lose all hope .If it does not get better but one is well enough to go back to work and almost normal that gives hope. …. Yes, one should not take away all hope.'(Carer Patient 3, Interview 1)

Relating with patients in a professional way

Treating patients with respect

Participants argued for the need for healthcare workers to treat patients with respect and behave in an acceptable manner towards them even if the patients were not as educated as they were. They suggested that for better care, health workers need to be trained in how to relate with patients, as they all have different backgrounds and upbringing and needed to be more professional:

'There is one health care worker, I know what she looks like but I do not know her name, I gave her a book when she was asking me my name because I could not talk I was so breathless, she threw back the book at me. I thought to myself what does she want, she threw the book at me and said don't you have a mouth. If she had not heard she would have helped me and asked me again. So it is not good, they need to be trained. This should be worked on.' (Patient 16, Interview 1)

Giving feed back and involving the patient and family

Participants thought that better care should also involve a relationship with health professionals where the patients and their relatives are not just passive, but there should be information given after clinical examinations and tests, so that they know

what is going on and they should be involved in decision making about their treatments. Most patient-health professional relationships in Uganda are still paternalistic and whilst many patients do not challenge it, a few now feel the importance of being involved.

> *'The most important thing is to also let the patient know what is going on. I have noted that when the health professional checks you with their tools they will not tell you that this is like this or like that, he just writes, the next health professional then reads and will also keep quiet.' (Patient 3, Interview 1)*

> *'Sometimes after they have seen our patients I cannot understand what is written in scan but they do not explain to you anything they just go away, but you are the doctor and I have come to you help me understand at least give the information to the patient if you cannot give it to the carer but it is important to know what is going on. ..Some health care workers are too tough also they should change.' (Carer Patient 18, interview 1)*

Participants sometimes felt coerced by health professionals against their wishes to take on some treatments which had previously caused very bad side-effects, and if they refused they were forced to leave hospital, they felt this needed to change.

> *'They decided to put him back on dopamine but we did not want it anymore considering what it had done before so we declined and my family declined having it. So they took off the drip and the next morning some staff who came to check patients in the morning started chasing us saying 'what is he doing here if they refused dopamine let them leave the ward'. When it came to chase him from the ward there was nothing to do and so he accepted that they put it back on him.' (Carer Patient 8, Bereavement Interview)*

Summary

This chapter explored patients' perspectives on the services available to meet their needs, how they met or failed to meet them and their suggestions on how care could be improved. The patient interviews revealed many health system challenges which led to unmet need. These included: a lack of medicines; a lack of information; overcrowded clinics; a lack of equipment that contributed to delayed diagnosis; overstretched health professionals who were not empathetic; and lack of services to support patients, spiritually, psychologically and socially. They suggested several improvements in the health care system and the conduct of health care workers as a means of making care better.

CHAPTER EIGHT

8.0 Introduction

This chapter brings together the perspectives of a range of health professionals who care for patients with HF. Professionals were asked to explain their understanding of the needs of these patients, the care that they believed they required and what services they understood to be available for patients. The chapter addresses study 4 objective and sections of objective 5

4. To describe health professionals' understandings of patient needs, care required and service availability.

5. To capture from both patients and professionals perspectives on what would constitute better care and how this can be achieved.

8.1 Health professionals' understanding of patients' needs and care required

All the health professionals (HPs) interviewed recognised that patients with HF had multidimensional needs, describing needs within the following standard categories of physical, psychological, social, spiritual and information needs. Their accounts of the patients' needs was a combination of what they as HPs perceived and what they thought patients needed, and those needs patients had suggested to them during their previous interactions with the patients.

8.1.1. Health professionals' perception of physical needs of patients

All health professionals' recognised that patients attended with physical symptoms and signs of advanced disease and needed treatment for those symptoms.

> *'The patients come with shortness of the breath of-course the different degrees, um usually we don't see people with stages one and two that is New York Heart Association stage 1 and 2, they are either at health centers or district hospitals they come here in New York Heart Association stages 3 and 4 and those are very sick and have body swelling, pedal oedema or ascites. Some have arrhythmias usually it is our clue to what could have brought them to hospital and they need relief.' (HP3)*

Professionals described cardiovascular symptoms and symptoms related to renal complications of HF. None talked of other symptoms outside the cardiovascular system, such as pain and nausea, which patients had described in their interviews.

This would appear to indicate that these symptoms are either under recognised by health professionals in practice and attention is given to symptoms directly related to the heart disease, or that these symptoms are not regarded as significant in impacting on patients' lives. Health professionals did recognise the need for a good quality of life and the need for restoration of the ability to perform daily activities, as a reason why care is sought and why some medications were preferred over others.

> *'They have of course um difficulty in breathing, body swelling, some will have chest pain, then, renal problems like reduced urinary output, because the blood pressures are so low, weakness, dizziness, reduced function they can't do what they used to do … Their quality of life is affected because they are limited in how much they can do,they need other people to support them for example if you have like stage 4 heart failure, the moment they get up they feel they want to sit again. So when they feel they are in trouble they come to hospital they get the Lasix and go back. That is actually what I was telling you when they come they get care in hospital which makes them feel good.' (HP4)*

> *'The physical symptoms are …usually the main ones it is usually difficulty in breathing, body swelling, easy fatigue, some of them report nocturnal cough although it's not very common, othopnea and PND some of them have reduced urine output mainly those are the symptoms they come with. Of course some others like in rheumatic heart disease and dilated cardiomyopathy and hypertensive heart disease present with palpitations. Yeah….. I think because lasix gives them quick relief the difficulty in breathing kind of like goes down they pass urine and they feel like they are light. I think they prefer it, the other medicines their effects you can't see them like immediately as in, they are hidden in most of them. They end up choosing some medication like lasix over the other medication.' (HP 7)*

Need for particular treatments

Health professionals noted that some patients and their family carers came with preconceived ideas of what treatments a hospitalised patient should receive, and they demanded such treatments. Some of the treatments requested reflected patients' misunderstanding about the nature of their illness and common myths and beliefs about illness. For example, it is a common perception in the community that if someone is very ill and has been hospitalised they need to be given intravenous fluids because they are not feeding, and there is belief that this will help them recover faster so they often demand for the fluids and it is difficult to convince them otherwise. This may explain why in the patients' interviews patients were given these fluids in private clinics. But in the case of HF this may worsen their condition because patients already have fluid overload with fluid in their lungs.

'Like ABC a patient who has now passed on she had much water in the body but her skin was dry so her relatives wanted us to put water (IV fluids) on her, yet her chest was wet the heart was so sick. So you have to explain why you are not putting water (IV fluids) because of their wet chest. They are usually not happy with this and it is not very easy to convince them. For them they want water and they keep on telling each other that their patient lacks water (body water). You again have to explain that the way the abdomen appears and the way the patient breathes shows we cannot strain the heart as they wish. You have to explain by encouraging them to take drugs to reduce on the water and the swollen abdomen and improve the way they breathe. Yeah' (HP5)

8.1.2 Health professionals' understanding of patients' psychological needs

Health professionals recognised that those patients with HF had psychological needs which included:

Need for counselling

Health professionals felt that counselling services were needed for those with HF and their relatives to help them to come to terms with their illness and to enable them to go forward, and in order to get support from family carers.

'Yes there is need to support them socially and of course aaa emotionally by counselling something like that to help the relatives to show them love and so that the patient can accept their illness' (HP8)

The need for emotional support

Health professionals felt that patients, particularly younger ones, needed emotional support as they experienced distress due to loss of function and as they became more physically dependent.

'They are distressed because they are unable to care for themselves because they easily tire and they feel they have to rely on others to care for them. This is a big challenge for someone who has been able to care for themselves and sometimes these are young people. For older ones maybe society may have prepared them to slow down as they grow old but for the young ones they have even a bigger challenge because they feel that now suddenly they have to be catered for by others.' (HP 1)

Health professionals recognised the impact of the losses the patients had and the feeling of being a burden that led some patients to the brink of depression.

'Some of them were like the bread earners and now they are depending on people who were depending on them so that actually stresses them. I have met a few who are really bothered at one time I thought they were really going into depression they felt they were not as useful as they were and it was bothering them.'(HP4)

Need for reassurance and to allay anxiety

Health professionals also observed that patients had anxiety and worried a lot, especially when newly diagnosed with HF, when they had severe symptoms which needed special treatments such as oxygen, and when they thought they were going to die and therefore needed reassurance at those times. This was similar to what patients expressed in their interviews.

> *'Patients come with a number of problems most of them are anxious they are getting a unique experience especially the first timers and they have no idea what is happening most of them think they are going to die.' (HP 1)*

> *'And then um they worry a lot. Like I had a patient with um really advanced rheumatic heart disease, she had been on oxygen for a long time, and she was 21 years, she had a child who was like 4 or 5 years and then she one time asked "doctor will I ever get off oxygen?" I was always… I kind of did not have a straight answer for her. I was like let's take one day at a time. I have seen many of them are worried about death and then the uncertainty about the way….' (HP7)*

The need to address impotence and its impact on men

Health professionals felt that in men with HF there was a particular need for assessing for the presence of impotence and its impact on them because some medicines used to treat HF caused impotence and it was highly prevalent, but patients were not free to talk about it unless they felt comfortable with the health professionals yet it impacted them significantly. This need had not been identified in patients' interviews and the reason for this could be because the interviewer was female and men may not have been comfortable talking about their sexual issues.

> *'Impotence is very common especially among the men, we always have to ask about it. Because one of the medications. It causes impotence in men. Carvedilol I think in some men I think it causes impotence, they may not tell you but because for me I am familiar I ask them then they tell you. So there sometimes you may have to get into real counselling and also find if there is an alternative medication to that yeah.' (HP2)*

> *'Because like people are increasingly telling me like the men loss of libido. Of course once in a while you engage them and make them lively and feel free with you. You chat a few things here and there but them coming openly not really.' (HP4)*

Need for security and to be valued

One of the most significant findings from health professionals was their view that patients needed to feel secure. They believed that patients chose to stay in hospital longer because they felt secure there. This was particularly true in situations where patients were not well cared for at home or if they were abandoned because they had become a burden, therefore in hospital they felt safe because they were valued and cared for.

> *'They need a lot attention and to be cared for. So they always need you they become as if they are…, how should I term it, dependent? Yeah, they need help from you. And we find that some do not want to go home, they become institutionalized. They are very many from cardiac side, who become institutionalized, they feel like not going back home you discharge them and they come back after few days. Yeah, because they know they are safe here. At times when we do not interfere a lot, but when you go deep or when you have time for them, they can disclose that they are not wanted at home, because of their sickness, that sickness which does not go. Mmh. Yeah, they become a burden at home, so they look for where they can be helped.' (HP6)*

Other patients felt secure in hospital and their condition stabilised because they had an opportunity to get away from social stressors at home such as opportunistic people who wanted to take away their property because they had been rendered helpless by illness, old age and being widowed. It appears that in some patients the stresses at home contributed to a worsened physical state and so they felt more secure in hospital.

> *'I have experienced this a few times, usually old women when they go home HF worsens, when they come back they are better after stabilizing them for a few days. So sometimes you end up keeping someone for a month when they are okay but they request that they don't want to go home because others say people are taking their property, people taking their land, or there are no people to support them, or because relatives think they are weak so they disturb them usually the elderly and men who are widowed they prefer to stay in hospital for a long time. Yeah that issue is there although we haven't explored it well.' (HP3)*

8.1.3 Health professionals' perception of patients' social needs

Health professionals spoke freely and easily of patients' social needs and this may indicate that these needs were the ones that patients were most outspoken about, and the ones that most directly affected the care health professionals gave to patients. The social needs of patients, as identified by the health professionals, included:

Need for financial support and financial security

The need for financial support and security was noted as important to enable patients to get medicines and to get transport to go for follow up care in the hospital clinics. Health professionals noted that a lack of financial security also led to patients being abandoned. One health professional explained that once men who were the sole providers for their homes became ill and lost their jobs and had no money, their wives left them. This is a finding that was contrary to what we found in patients' interviews which only revealed that it is men who left women who are ill because of failure to perform their roles.

> *'The finances always give them a lot of hard time because they don't have all the money to buy all the medications at once.' (HP 7)*

> *'You see now like for a man women also run away from them sometimes they attend to them but eventually later they run away. And remember poverty is another thing because when you are not working you are not earning you are nobody, so that how it is.' (HP 8)*

Need for better nutritional support

This need stood out in patients' and health professionals' interviews as being very important and common. Health professionals argued that some clinical symptoms, such as body swelling in those with HF, could be attributed to malnutrition (resulting from unbalanced diets because of lack of money) as well as HF. This highlights the importance of addressing this need to reduce on symptom burden as they explained:

> *'Nutrition is a big problem.. so I think that they need that support. Um colleagues of ours in South Africa, Cape Town are XXX and others, they have done that before and followed up heart failure patients and their nutrition that is balancing up the diet and salt, putting some protein in the diet. You see because patients are not working, they cannot raise income for themselves and even food. So they get malnourished and when you see someone you think it heart failure when it is more than that. So I think it a big component which is lacking.' (HP3)*

> *'He needed to eat and drink all the time but we did not have money, we do not have that money and resource in the hospital. The food is a problem.' (HP8)*

Need to be accepted in the community

Health professionals noted that patients wanted to be accepted with their condition in their community and not to be associated with feared or stigmatised conditions. The

challenge of integration and the consequences of being seen as separate or odd was particularly pertinent for those of school age. The professionals described how there were misunderstandings when children were out of school, a common one being that the child was HIV positive, rather than having a heart problem. This was because most communities didn't fully understand the seriousness of HF and didn't realise that it could debilitate a person such that they were unable to carry out normal daily activities.

> *'Then of course like the school going children because we see a lot of rheumatics. We have a registry that we run and I see some of them. Their challenge is these frequent visits to the clinic then actually recently some were talking about stigma. A few of them are actually stigmatized. Especially those who go to school, because you know some people don't know that heart failure can make someone like if your heart has failed it will make you be in hospital off school for sometime. Like I have seen people been mistaken to have HIV. Whenever they come for follow up they say my classmates think I have HIV you really see they are concerned then they try to explain to them.' (HP 4)*

Need to live a normal life and have normal biography/ life course

Health professionals understood the desperate desire of almost all patients to live a normal as life as possible. Patients, they explained wanted to fulfil their dreams such as having children and family. This was also identified in the patients' interviews.

> *'There are a few of them who have had issues like they want to conceive but have rheumatic heart disease and mitral stenosis and we have told them the risks, it is a bother to them because if you do not have a child you want a family and we are telling them you have to first sort out the valves and the options are limited.' (HP4)*

Need for support from family members to provide practical support

Health professionals had observed that some patients had no family carers while in hospital, indeed some were abandoned and had no one to help them at home, yet they needed practical support to meet daily needs and perform activities of daily living as all of them had markedly reduced performance status, and to get medication and food. It is the norm in Mulago Hospital that family carers provide practical support for their ill relatives such as giving them oral medications, feeding them and washing them because of the huge health professional to patient ratios. The nurses mainly provide injectable medicines and any other care which requires technical expertise. There was a sense from health professionals that they could understand why relatives were not attending to the patient (e.g they had to go back to care for those in the homestead),

but this is an exceptionally challenging situation in all HF patients because most are unable to perform activities of daily living and this increases the workload on the already strained nursing staff if they do not have a carer with them.

> *'There is one gentleman who had a swollen abdomen, his relatives had abandoned him and Dr. XXX got him treatment but the medicine was very expensive, he had to buy, that one was rejected and abandoned in fact I went to Kawempe and I looked for the relatives and they promised to come and some came. You know when you get ill for long people get tired of you. But It is hard for the doctors when a patient is critically ill and may need a CT scan, but there is no relative to tell lets buy this medicine, let's do this investigation etc.' (HP8)*

> *'They even become a burden to the parents to the extent that they leave them alone in the hospitals unattended as the parents have gone away to work, like one of our patients who has just died, they used to leave her alone in hospital and the parents went back home to look after the others. They need support like going to the bathroom, yet there is no one from the family to help them.' (HP 5)*

> *'There are those ones who come, they do not have attendants and they need a lot of help - we make sure that you set everything for her like those ones who cannot go out of bed, who are bed ridden , we have to collect food for them, we have to do everything.' (HP6)*

Health professionals recognised the need for patients to be close to their families while they were away in hospital to meet their relationship needs. Family members are welcome to visit their patients in hospital but children, especially infants, are not allowed on adult medical wards for fear of contracting infection, and this is a big challenge for ill mothers who have young children at home.

> *'The same patient she asked me "doctor can my child come and see me?" so I was like okay, yes she can. I told the relatives to try and bring the child to see her and she actually passed on a few days after that. So you can see that they have a lot of* concerns. *They miss their families when they are in hospital'. (HP7)*

8.1.4 Health professionals' perception of patients' spiritual needs

Only one health professional talked of HF patients having spiritual needs. This may mean that spiritual needs are less recognised by health professionals or less expressed to health professionals by the patients. The spiritual need identified by the health professional was the need to pray and invoke divine help in addition to medical treatment.

'A number of patients have told me that fine you have given me these drugs but am also going to pray, okay, and I do encourage them to pray it but I also encourage them to take their drugs. Yes.' (HP1)

8.1.5 Health professionals' perception of patients' information needs

Information needs were only acknowledged when health professionals were informed that patients had expressed a need for information in their interviews, but they did not come out as a perceived need from the health professionals before that. This probably implies that prior to informing them of the patients' need for information, health professionals could have thought it may not be an urgent need or that patients do not understand medical information, as one health professional explained:

'*Patient education, I think we are not doing enough. One because may be patient volume is too much but I think two I don't know whether it is true the assumption that patients don't understand the information and I think they actually do.' (HP 3)*

Health professionals thought that patients wanted information on the prognosis of their illness and diet and they acknowledged that sometimes the conversations on prognosis were difficult.

'They want to know especially in villages, what type of food to eat. Because when you talk about the salt free diet they complain that how can one live without salt so you have to explain about salt and certain foods that the patient should eat and not eat.' (HP 5)

'Sometimes you may think they know the prognosis and then you come and they ask questions which show they think they are supposed to be get better and then kind of like go back to their normal life it always brings hard questions to discuss.' (HP7)

8.2 Health professionals' perceptions of services available for heart failure patients

Health professionals described several services, which they believed to be available to meet patients' multidimensional needs. However most of these were not mentioned by the patients in their interviews and this may be because they were not accessible to them financially, or they were not made available or known to them. Health professionals also identified barriers and challenges to good care that were intrinsic to those available services that resulted in unmet need.

8.2.1 Services available to meet physical needs

Services available to treat physical problems for HF patients included diagnostic services and treatment services.

Diagnostic services

Most health professionals' view was that diagnostic services had become more accessible to the patients, especially in Mulago Hospital, in the recent past because more equipment had been brought into the hospital. However, they recognised that in the lower public health centers these services were still lacking and even basic diagnostic equipment, such as those for measuring the blood pressure, were lacking in some centres. Patients therefore had to go to private clinics where they could access the services and had to incur costs in those clinics.

> '*The diagnostic services have become more available in the last few years, the chest X-ray, the ECG and the echo are all available here in Mulago. On ward 4C we have 2 echo machines; in the heart institute we have 4 ECHO machines so that is within Mulago Hospital and of course there are others in the private settings. So all patients in Mulago Hospital are captured somehow.' (HP3)*

> *'Actually I physically went to Kk Health Centre because it's near Kampala here and even the BP machine wasn't there. Actually it was surprising, there is a clinic opposite, so the doctors and nurses there they send someone to the private clinic to have their BP taken then they come back to the health center for treatment but they have to pay in the private clinic'. (HP4)*

Treatment services

Health professionals observed that available treatment services included medical and surgical treatments, and these were delivered through in-patient and out-patient settings. In Mulago Hospital in-patient and outpatient services were provided in the general and private settings. The private setting is the Uganda Heart Institute and here services are paid for at a subsidized cost.

In–patients services

Services offered in the in-patient setting included services for critically ill patients, such as the intensive care unit and the coronary care unit for cardiac patients, as well as the general cardiac ward which was for those who did not need critical care. The services for critically ill patients were mainly in the private wards and therefore

needed to be paid for but an arrangement had been made for those on the general wards who needed this care, to get it free of charge on the private wing. This was mentioned by a health professional working in both the heart institute (private setting) and the general ward but not the other health professionals, probably because it may not be very practical as the patient load from the general side who need the service may overwhelm the private service.

> '*Those who need to be admitted in the general ward will be admitted there, the heart institute charges some money because there is the system of cost sharing and if you cannot afford this you go to the general ward. But we have a linkage where patients who go into cardiogenic shock from the general ward can be brought into the intensive care unit in the Heart Institute and treated free of charge. In the intensive care unit for heart failure we do advanced monitoring of patients.' (HP 3)*

Out-patients' services

Health professionals noted that there were outpatient HF clinics, those in the public setting run once a week and those in the Uganda Heart Institute were run every day. The outpatients' service in Mulago is where patients who are stable and patients who have been recently discharged from the wards are followed up and continue to get assessment of their HF and their medical treatment.

> *'We have out-patient clinics, Thursday is the out-patients' day and everyone goes to that clinic. Some patients come to the Heart Institute, the Heart Institute clinic runs every day because the patient volume is less but we are the same group of doctors who run the general out-patients' clinic and in the Heart Institute. (HP4)*

Medical treatments

Health professionals noted that there was improvement in the availability of different types of medications needed for treatment of HF over the years, although the supply was not yet consistent leading to frequent stock outs.

> *'There are many drugs at the moment that are available that have not been available. I don't know whether I have been around for a long time but I had never seen them before. Okay.. but they are increasingly becoming available the supply is not yet good enough, but given where we come from I can say we have come a long way.' (HP1)*

The medicine supply was better in the Uganda Heart Institute where a system of cost sharing existed and therefore patients were able to have a consistent supply of all the required medications, but on the general wards and in other health centres it was noted that a few medications were not available, partly because the essential drug list

does not include some of these medications and the government only procures drugs based on this list.

> *'Of course the other services are medications, the Heart Institute because of cost sharing tries to get all medication. The government allows it to have a wide range of drugs. But on the general ward the government buys drugs based on essential drugs list and the essential drugs list for the heart are very basic usually they have nifedipine and captopril only and yet heart failure is complex disease that requires a number of medications. The average heart failure patient requires six different drugs which are expensive. So if the government is not providing, only those who can afford these drugs, and usually they have to go to private pharmacies and buy the drugs. So typically when I see a patient I give them medication for three months, they will probably buy for two three weeks and then they come back worse.' (HP3)*

Surgical treatments

It was clear from the descriptions that the surgical services available to patients were understood and defined by the professionals as highly specialised services. These stood out as markers for the health professionals of reaching a level of competence in cardiac care. They did recognise the high cost and the limited availability of the treatments and the need to avail these services for the most common causes of HF in the Ugandan setting such as rheumatic heart disease.

> *'We recently started inserting ventricular pacemakers just before transplant if patients are not responding to treatment despite optimizing the medicines. We have so far done 4 and we hope are doing 2 more this Saturday. I actually had training for that as part of my PhD I did that in South Africa. It is still very expensive even when we do it from here, it came down from $12,000 to $8000 then $5000 so there is hope that more people will get it as it comes down.' (HP 3)*

> *'For the intracardiac devices they are mainly in the Heart Institute, they can get pace makers, they can get cardiac re-synchronization therapy, those with myocardial infarction can get a percutaneous interventions as an emergency.' (HP7)*
>
> *'The valvular surgery is not commonly done, we do in some patients with mitral stenosis which is not complicated with other things, we have been able attempt closed valvoplasty that is you push in a balloon and try to rupture and widen…. But open valve replacement was done once and the surgeons' team has not been keen about it, there are reasons why they have not been keen about it, first of all it is very expensive you have to buy the valves and the program starting valve surgery is more complex that the congenital surgery where by you close that hole and that is final it heals but this one you have to go back when a patient grows bigger the valve is small for them and you have to go back and put another valve so the people funding do not want something where they will not show results quickly so it is not done here people have to travel abroad.' (HP2)*

8.2.2 Health professionals' perceptions of services available to meet information needs

There were no formal single or group sessions organised to educate participants about their illness, medications and self-care. There were no written, pictorial or oral materials designed to provide information for the patients, as a result information was inconsistent and confusing. Health professionals confirmed the lack of these materials but said they often gave patients information, although it may not be adequate. The information they gave patients was on their diagnosis, the need to adhere to treatment, some side-effects of treatment and the need to come for review. They felt they needed to start giving information on the prognosis as well.

> *'In most cases when we see them (patients) we tell them about their diagnosis and we tell them the need to take medication almost for the rest of their life. In most of them what I see which really lacks in the information we give is uuum, is their prognosis especially the stage 3 and stage 4 of heart failure. We should be telling them about their prognosis but we miss that part. Diagnosis and treatment we usually tell them, we tell them about their need to adhere to their treatment in some cases we give them information about side-effects of the drugs they are taking and then the need to come back for reviews when they are discharged from hospital yeah.' (HP 7)*

8.2.3 Health professionals' perceptions of services available to meet psychological needs

Health professionals reported that psychological support was given to a limited extent by nurses on the wards, who felt it was part of their responsibility to counsel the patients, especially about hospital stay.

> '*So our work as nurses then is…. we do talk to them (patients), by counselling them, showing them that although they are sick they should not be on the ward throughout. We have to advise them.' (HP 6)*

The social worker viewed her role as that of giving psychological support to patients and their families in order to enable them to live with their illness and so that they could get support from their families, and to prepare patients and families for the costs involved in the care.

> *'We come in sometimes to help them emotionally…. we counsel them about their diagnosis to accept it, we counsel their families to love and support them and we counsel them on the costs of treatment because isn't it very expensive? (HP 8 - Social Worker)*

8.2.4 Health professionals' perceptions of services available to meet spiritual needs

There were no formal services organised for participants to meet their spiritual needs in the health care system. However, spiritual support was provided in the health system as an initiative of the spiritual leaders and members of different faiths who visited the hospital to support those members of their faith who were willing to receive support.

> *'We the nurses do not really give spiritual support but we really get pastors, we really get churches that come in and…. almost every Sunday and in the evenings the born-agains come in.' (HP 6)*

In Mulago Hospital there are three religious denominations which have their places of worship on the hospital complex, and this may have facilitated these religious leaders accessing patients from their religious denomination, but there was no mention of formal consultation made for spiritual care by either the participants or health professionals who were interviewed.

8.2.5 Services available to meet social needs

In Mulago Hospital there is one social worker who provides services for the 9 units in the medical wards, of which the cardiology unit is one. Given the burden of social need, some of the work of the social worker was done by the nurses on the wards who felt it part of their job to provide these services and they would refer to the social worker when they felt there was need.

> '*One of our jobs is keeping the patients in the right position, uuum talking about their condition, to reassure them, counsel them, giving them treatment, and even health educate the relatives as well. To those who do not have relatives in hospital, the nurses assist the patients in hospital like taking the patients to x-ray. Changing bed sheets, that is, bed making and even assisting them to position themselves well while asleep and other services.' (HP5)*

> *'Those ones who are institutionalised we call the social workers to solve their problems.'(HP 6)*

The services available through the social work department included provision of limited finances from the hospital to access medicines, supporting family carers so that they are able to support the patient and networking with community and volunteer organisations in the hospital, which were providing social services. There were a lot of resource constraints to support participants' social needs and most needs went unmet as the social worker had a limited budget.

> '*One patient was referred to us because he could not afford medications, they were very expensive. But for us when we are contacted as social workers there*

is an organization that we contact and they can provide a little money for drugs and investigations. One patient was rejected and abandoned on the ward so I went to Kawempe his home and looked for the relatives because when you get ill people get tired of you but the mother was there. Then another one she came and after delivery she got heart failure and the husband rejected her. A good Samaritan brought her to Mulago and I was called. So I was called because of the baby so I looked and got a temporary home for the baby until she got better and counselled her about domestic violence and rejection by men. When they discharged her we took her home. ' (HP 8).

'COEM is a Christian voluntary organization that used to help but their funds have also run out. But they helped a lot in feeding patients and cleaning them up but their number has now reduced because of no funding. If at all another NGO would come up the can use the same the same volunteers because they are not paid but they just do it as Christians.' (HP 8)

8.3 Health professionals' perceptions of barriers and challenges faced by health professionals in caring for heart failure patients

Several barriers and challenges were identified by health professionals as affecting care. Broadly these can be classified into: health system challenges and patient and community related challenges

8.3.1 Health system challenges

The health professional interviews revealed gaps in the health system that presented as barriers to provide good care and these included: unavailable medications and an inconsistent supply of the required medications, inadequate staffing, failure to recognise the role of other non-medical staff in managing HF and failure to provide adequate information on the condition.

Lack of medicines and inconsistent supply of medications

This led to unnecessary visits to the hospital because patients had to return when their medications ran out and this was usually before their out-patient clinic appointment date. This exacerbated the problem of workload for the health professionals in the clinics who were already struggling, and was a challenge for the patients who because they could not afford their medication relied on the health system for their supplies.

'The challenge for the patients is usually lack of drugs. Lack of drugs can be looked at in 2 ways. First of all the drugs could be too expensive for the patients to afford or the drugs may not be available where the patient stays, so in a number of situations you find that they would wish to rely on the hospital for their stock of drugs and yet the hospital supply is not reliable. Someone

may have come from afar and expects to get drugs to last them until the end of their appointment and yet those at the hospital cannot sustain that so they only get some drugs. Someone is supposed to spend 2 months away but you find that within 2 weeks the drugs have run out and they come back sooner than they would have come. This becomes a burden to the hospital because of big patient numbers and also becomes a burden to the patient because they then have to travel back. So drug supply is a big issue that can be part of the hospital problem or ministry of health problem, but also poverty on the part of patients plays a big role.' (HP1)

Health professionals explained that they had to give sub-optimal treatment because of a lack of the medicines and therefore patients never got the maximum benefit from medical treatment, yet if optimised there was potential of reducing the number of hospitalisations.

'Though of course the other thing is the way we give them medication because of the challenges we have we don't give them the full, .. like the doses are not optimal sometime. Most times actually they are not that optimal. You find that you only give them an ACE at a later point you have to introduce a B blocker slowly, spironolactone increasingly we are starting to use it because when someone improves we introduce some new drugs and that can actually make them not come back to hospital. Yet on their prescription you find lasix and digoxin sometimes an ACE, sometimes a B-blocker, of course carvedilol would be useful but it is expensive …but of course the challenge is sometimes is the cost aah … sometimes we have free samples that we give them but it's not sustainable.' (HP4)

Inadequate human resource

The accounts from the health professionals revealed gaps in human resource planning in the health system. They observed that staffing, especially for the nursing staff, was very low for the number of the patients cared for in the service and although there was much being done to improve services for those with HF, the number of nursing staff had not been increased and yet most of the care was left to them.

'Another big challenge I have seen is nursing care, we have very thin cadre of nurses on the ground. So ultimately, however much one invests in these services there must be a nurse to give them the drug, these must be a nurse to teach the patient, there must be a nurse to turn, to comfort the patient so there is still a long way to go in terms of nursing care, because most of these services are eventually delivered by the nurse. The big challenge is still man power.' (HP1)

Failure to recognise the roles of other professionals in heart failure care.

Another health system challenge observed by some health professionals was the predominant thinking that HF care was only bio-medical and therefore the role of some non-medical professionals such as social workers was reduced to just finding help for those patients who had failed to go home because they had no transport fare. In most of Uganda the approach to most diseases is bio-medical, except for cancer, where palliative care is now integrated.

> *'There is need for a social worker in this condition except that most health professionals have not recognised it yet. They think that our only job is when they discharge patients home and we look for money for transport but we have other important roles I have seen for example that when we trace relatives and they come and work with the doctors even the patient gets better sooner.' (HP8)*

Failure to provide adequate information

Health professionals acknowledged that they gave insufficient information to the patient because of system challenges, such as high patient loads, that made it impossible to have meaningful time to communicate and give enough information:

> *'I think sometimes because of the numbers we do not like....we don't give them adequate information like explaining to them. Because like every once a week I do Echoes down there (Heart Institute) but I realise… you know once you are on that bed there are many patients waiting outside. They are many then someone may ask doctor my heart what is the problem? Then of course you tell them a few things send them to the doctor who sent them to you but sometimes I used to sit in the cardiac clinic and I imagined, you know, we send them to these clinics but how much information will they be given? Of course it depends on who is there, they give them information but I realised the information we give is too limited. Like today they were about 110 patients in the clinic. That is the minimum because we were four doctors who were seeing these follow ups.' (HP 4)*

8.3.2 Patient and community related factors

Patient and community related factors that deterred good care included: presenting with advanced disease: presence of co-morbid conditions; poor adherence to treatment; inadequate self –care; lack of community support; and poverty of resources.

Advanced stages of illness

Most patients presented to hospital in the advanced stages of the illness and health professionals explained that at this stage, when there was much structural damage, it was difficult to reverse the clinical course and hence resulted in poor clinical outcomes.

'Their clinical course is very poor, because usually our patients come very late irrespective of the cause. The commonest cause of HF here is usually high blood pressure, followed by cardiomyopathies and rheumatic heart disease all these patients present very late and when they do usually we try to intervene get them the necessary medications but because of the challenges one for that late presentation and sometimes they don't get all the medications that you want them to –um so by the end of one year 20% have died and this pattern is seen in the whole of Africa so it is very poor progress. They die because of sudden cardiac death which is like end stage heart failure and so they end up getting lethal arrhythmias like ventricular tachycardia or ventricular fibrillation. But, majority also die from pump failure like the rheumatic ones. They get volume overload for a long time then they fail to respond to medication then they just fail to pump the pressure goes down. Yes they just die a lot and I have been lucky to follow up the ones with rheumatic heart disease, because we were participating in a study so they have special care when they come in so most of them have died from hospital despite giving them everything. They were put on ionotropic support, all the medication but they still died. The heart just fails to pump from chronic volume overload.'(HP3)

Presence of co-morbidities

The presence of other medical conditions, such as anaemia and infections, also deterred good care, as they often led to the worsening of the HF and repeated hospitalisations, as this health professional explained:

'Other times they get superimposed infections, pneumonias, malaria and they come back in heart failure. Most of our patients are anaemic, most of them have poor nutrition. So they are prone to come back to hospital because anaemia really drives heart failure in most cases.' (HP7)

Poor adherence to treatment

Poor patient adherence to treatment was one of the challenges to good care identified by the health professionals who reported that it was both a patient related problem due to ignorance and failure to accept the gravity of their problem, and also a health professional related problem, because the health professionals did not provide information to avoid this problem.

'But sometimes it is also ignorance or lack of information from health workers. Many patients once they feel okay they stop the medication because they think they are cured, patients always think that once I am sick I have to be cured when they feel better they are sure they are cured, they will stop even after you have told them this is a chronic illness they still think there is a cure out there, okay? So that is the biggest problem. Sometimes we fail to tell them that this is a chronic illness and you must take your drugs like for a long time. Now for a young person you tell them you are starting drugs now and you will take them forever, they will kind of say aaaha, not me they will kind of don't

want to believe it and they will try to test and see whether they are drug dependent or they are cured.' (HP1)

Lack of family and community support and poverty of resources

A lack of family and community support was noted by some health professionals as a barrier to good care. They explained that most patients, because of their declining performance, lose their jobs and their source of income and have to depend on their family and community to support them financially to come back to the hospital for follow up care and to buy medication. However, probably because the community is also constrained with resources, they will only cater for those who are very ill and therefore it is not until they get to the stage of being very ill that they get support to come to the hospital. Then they have to incur transport costs and costs of drugs and all those costs related to being hospitalised and the hospital also spends more on very ill patients as compared to a stable one.

'Society is such that people do not give these patients money to come back until such a time that these patients are so badly off that they have no option but to send them back and the little money they would have used to buy drugs you find is used for transport and hospital expenses. In other words you should have kept the patient at home with drugs but then you use money to transport the patient yet always salvaging the patient is much more expensive for the hospital and for the patient themselves if you factor in the inconvenience , the pain and the disturbance the patients go through then it becomes a real nightmare.' (HP1)

Inadequate self-care

Another important patient-related barrier to good care was identified as the lack of adequate self-care, which the health professionals attributed to patients' resistance to adopting new healthy lifestyles. Most people in their homes cook food together and it would pose an extra burden and cost to have food prepared separately.

'Other times um other lifestyles like salt intake, intake of free water like too much free water always drives them to heart failure and they keep coming back in hospital. But still you know diet is something very hard for people especially salt. Of course you don't tell them to go off salt but when you tell them to take little salt if someone has been used to a lot of salt they kind of sometimes don't do it and continue take salt and things like that.' (HP7)

8.4 Health professionals' views on the care required and how care can be improved for patients with heart failure

All health professionals believed that there was room for improvement in the current care that was being offered in order to meet the needs of the patients. Most of them emphasised improvement in care for physical problems and particularly targeting the cause of the illness, but some also recognised the importance of meeting other multidimensional needs. Health professionals suggested a variety of ways of improving care:

Building capacity for staff in lower level hospitals and health centers.

Health professionals felt that once the capacity for the above mentioned was improved, so that they have skills to use the new available HF medicines, and if the lower centers were well stocked with medications and well equipped with some basic diagnostic and treatment services, then more patients would be treated there. Thus reducing on the patient load in the national referral centres and improving services in both settings.

> *'Retraining of the health workers in lower hospitals and health centers to expose them to these drugs is very important otherwise we have no way out. The Ministry must deliberately go out and sensitize and pass on information on how to use these supposedly new drugs. Okay? So we are still growing in that area but a big challenge is still man power. We still have a duty to train manpower.' (HP1)*

Health professionals had noted that patients seen in Mulago Hospital came from all over Uganda, and once they referred them back to their nearby health facilities they often came back claiming the health professionals in those settings could not treat them, and there were no medicines available.

> *'We have tried to decongest the hypertension clinic on Monday clinic because every day there are 250 patients about 80-100 new ones, some of them are stable so when we with Dr. YYY we tried to send them back to their local hospitals and health centers. Few went and they said where you sent us where there were no people, there were no doctors, no nurses and there were no drugs; that's why they came back to Mulago. So I think it has to take a broader outlook to strengthen the referral system. Level 3, 4 and regional hospitals have to function. Once they do, it's easier to see them from there. They do not have to be physicians at those centers because once a diagnosis has been made and the patients medication is known then just like we do with HIV once you know someone is on this we should train junior doctors how to continue, they should be able to continue.' (HP3)*

Increasing trained staff numbers in the referral hospitals.

Health professionals cited lack of staff as a major barrier to good care and argued that training more staff, and deploying them on the cardiac wards and clinics in the national referral hospital, would lead to better care. Emphasis was placed on the nurses as HF patients needed a lot of nursing care but the nurses are very few (it is not uncommon to have 3 nurses on duty on a ward of 100 patients) and some health professionals felt that nurses are better communicators and should be knowledgeable so as to give patient information.

> *'So we need to teach many… involve many health workers, all the nurses you know they are the people who stay more with the patients. They need to be taught about these what ? these diseases… how to prevent them, you know they need to be taught about counselling so that so that when the patient asks they can answer something. Because we the doctors are very few and then we are not really good counsellors and many times we cannot simplify what, , many of us we are not …we do not speak their language. We cannot simplify to proper appropriate translation. Yeah.' (HP2)*

Other health professionals argued that training nurses as specialist cardiology nurses would raise the standard of nursing care given on the cardiology wards since they will have specialist knowledge in cardiology, as opposed to the current situation in the hospital. Currently, only 3 nurses cover a ward of 100 patients with different specialised units and different body system illnesses and the nurses tend to have a generalist level of information and skills in each specialty.

> *'On our ward we need a special group of nurses to deal with cardio patients but the number of nurses is not enough, so you have to prepare for the whole ward in the end the nursing care is not effective due to the patient over load. We need nurses who have specialised in cardiology but they can be other nurses so long as they know what to do, but according to our ward we cover the whole ward with different specialties with pulmonology etc. We do not have special people doing cardiology therefore we have a problem.' (HP5)*

Some health professionals proposed that by having more nurses trained they could also offer some of the services doctors offer, therefore reducing the workload of doctors. Probably the health professional was trying to advocate for the model that has been successfully used in HIV care in Uganda where more nurses have been trained to do patient follow ups and assessment and only refer to a doctor when they feel they need extra care. This is because in Uganda, there are more nurses trained per

year than doctors and therefore the nurse patient ratio is better than the doctor patient ratio, but there are ceilings to the number of nurse employed in government facilities.

> *'Other times I think that we should increase in the staffing of our nurses to help and to train them to know the basics of heart failure so that we increase on the critical number of nurses so that they can actually help us in taking care of these patients be it in hospital or at home.' (HP7)*

Improving the availability of medicines and other services for the management of heart failure in all hospitals

Health professionals proposed that there was need to avail the required medications for HF as they had noted that it is one of the major barriers to good care. They noted that in lower level health centres the medicines available were not the ones recommended for HF to improve morbidity and mortality.

> *'Then of course providing these drugs is very important. It's a challenge we, you know in our project,we work with students, they go to different sites, we just send them out and ask them to look out what is available there and ..down there…….....the medicines there are propanolol, atenolol and aprinox once in a while. So these other drugs ACEs, good B-blockers they are not there .They are not there.' (HP4)*

They observed that although there was significant positive progress in the use of advanced and sophisticated methods of diagnosis and treatment for HF in Uganda, the basic services and drugs were still lacking, even in public hospitals including the national referral hospital, where even equipment to measure blood pressure or to take patients' weight were not available.

> *'In hospital, our general cardiology ward still needs a lot of improvement to make, you know our wards do not have basic needs like a BP machine, a weighing scale, a measuring cylinder for urine output, things like that are still missing because the ward is too general. Once we have those I think clinical heart failure will improve and then we will be able to get things better.' (HP3)*

Also there was a mismatch between the available diagnostics and the care given, with so much attention being paid to the diagnosis, but once a diagnosis was made there were no services to treat the problems. This may be because with the on-going non-communicable disease campaign it may be easier to advocate for more sophisticated equipment with external donors, with the basics being left to local governments.

> *'I think the government has a duty to deliberately try to improve some of these services. If you invest money in a service and you don't go all the way then in a way that money is lost. If I can do a radiograph and not stent, I wonder how much of a benefit that is to me as a patient. That benefits a doctor more*

than the patient. So government should deliberately try to develop these services'. (HP1)

They believed that having specialised clinics run by specialists in those areas would motivate health professionals because they would be more confident in what they were doing and it would give them more time to communicate with the patients. Currently cardiologists in Mulago are few and due to the high patient load they have to see different heart conditions and are expected to perform all interventions. Although many have been trained as general cardiologists, they may feel overwhelmed doing all types of cardiology and would like to concentrate on one.

'Of course like we need … I do not know how to put it, down there in Heart Institute, I spend time with them because things move, and that may be gives me the courage to do more cardiology. We are in the move of actually having HF clinics, specifically HF, arrhythmia clinic such that someone goes to that clinic and when someone comes before you there, you know what they have and you can give them the time that they need and of course the other thing is people are in the discussions of specialised clinics not necessarily Mulago but wherever, like having a clinic, particularly having nurses committed to that, you have the doctors committed to that, you invest in drugs committed to that,' (HP4)

Providing information on heart failure and its treatment to patients

Patient and family carer education was considered by all health professionals as important in improving care and they talked of how it was already in their plan but that they had been limited in going forward with it due to a lack of funds.

'*We need to come up with flyers but of course the challenge is still getting some small fund which we can use to keep it continuous. But that is in our plan' (HP7)*

They suggested that they planned to provide information by use of flyers with information that was accessible to them in their languages.

'You know we need to make those flyers for patients, that is one thing but then also translate them.' (HP2)

Having oral and video education sessions in the clinic as they wait to see a doctor in the clinic on their follow up was also suggested.

'I agree we need to give information, actually Dr. Xx and some lady in Mbarara intend to put up proposal to see if they did counselling of some sort to hire some nurse with knowledge in heart failure who can give information. And also in teachings that people get as they are awaiting to see a doctor if someone is there to explain to them what they should do and their illness.

Yes we are trying to see how we can make this happen because even like using the screen there you can demonstrate some of those things as they wait because once they go in there (he laughs) the time is … they ask what is your problem….the contact is really minimal. There are too many patients over 30. So the numbers are huge.' (HP4)

The information that they thought would be relevant to communicate was that about self-care and lifestyle changes and information on the use of medicines and their side-effects. They felt the need to have standardised information and to have a uniform message and the use of flyers would address that.

'I think like we need to educate people to use medicines well and also to talk to the patient because the non-pharmacological bit actually like amount of water you take, reduce salt it is not really emphasised and those where you think its emphasised you find someone who is not taking salt at all and then they come in with hyponatremia so it's, I think, education is another intervention that we need to do, what message are we passing on and it should be uniform message so that even upcountry people can do what we can do this side.' *(HP4)*

'I think we are trying to come up with some kind of like flyers to give to patients especially to patients who have hypertension and heart failure and even other heart failure patients what to do when they are at home, how to take the medications and which side effects to look for like small flyers.' (HP 7)

Providing psychological support

Health professionals advocated for training health professionals in providing psychological support (such as counselling) to patients and their families. They felt that psychological support will improve family carers support to patients. It is interesting that some doctors believed that the nurses needed the training more because they had more contact hours with the patients and usually they are the counsellors. This may reflect the medical training which is anchored in the paradigm of bio-medicine where doctors are mainly trained to treat disease and will not think that providing psychological support is their job.

'There must also be now the counselling, there must be that component of what, of patient education and counselling a very strong program for that kind of you know… So, that one actually is quite a significant component of the management. Those who have chronic heart failure they are quite many, so you counsel the patients and the relatives so that you can get that support. So we need to involve many health workers, all the nurses you know they are the people who stay more with the patients. They need to be taught about these diseases, you know they need to be taught about counseling so that so that when the patient asks they can answer something. Because we the doctors are

very few and then we are not really good counsellors and when or many times we cannot simplify what, many times we cannot simplify what, many of us we cannot speak their language. We cannot simplify to proper appropriate translation. Yeah.' (HP 2)

Including palliative care in the comprehensive care of patients with heart failure

Palliative care was suggested by some health professionals as an important part of the comprehensive care for HF patients, but for many the old model of integration of palliative care in disease management still preoccupied their thinking and they suggested that palliative care would be for those in whom nothing could be done.

'Yeah... so within that kind of arrangement, we need to include palliative care Yeah, because there are those we know we can't do much, yeah, but you need to tell them so that they know the extent of their disease and what they can expect or whatever yeah. Then palliative care for those who where there is no hope of healing. There are a good number of these we know someone needs a valve but he is admitted but we know he cannot get it and he is just there waiting.' (HP2)

Some health professionals however, understood that PC was not for only for the dying but had several roles in those with HF and they understood these roles to include communication with patients and addressing psychosocial needs. This increased understanding may reflect the advocacy done by the palliative care unit in the hospital which is increasing awareness for palliative care in non-cancer conditions such as HF. However, it was noted that the role of palliative care in HF was not completely understood because health professionals did not mention symptom control as a role palliative care could play in HF care and it appeared that they thought the role of the PC team was to teach those working with HF to communicate, but the team did not necessarily have to be involved until the cardiologist had nothing to offer. This may explain the few referrals of HF patients to the palliative care services.

'There is a huge role for palliative care. You know previously we used to think palliative care is pain management, then for people who were dying. But we need it because the palliative care team will easily complement all these other units like even cardiology because we will learn how to communicate to our patients, we would be able to feel what they feel because sometimes you concentrate on what the ECHO and ECG says and science and medicine then you forget that these people actually you have given them something but they don't feel your intervention. So how do you merge those two and how do you support them and you know sometimes it's beyond the medicine. How do you prepare them to communicate to their environment and how do you address their other issues, psycho-social issues because you do not look there yet they contribute significantly. It has taught me in the hypertensive clinic if you are

free with a patient they start telling you issues "doctor I hope you do not blame me today, the medicines, I failed to continue with them this time, this medicine was not so good.' (HP4)

Health education of the public

Another way that health professionals thought of improving care was by educating the public on the prevention of heart disease, early recognition of HF and seeking care.

'But then also we have to get to community where people are not sick you know many may have subclinical heart failure but we need to address those common causes ,yeah. To go and talk about them, how to prevent the rheumatic heart disease, tell people to go and check for blood pressure before they could be getting that kind of disease and then of course the prevention, yeah. We need now to go into… so in counselling to talk to the relatives of the patients to learn the prevention, yeah.' (HP2)

'Then of course educating the masses of those early signs so that they may come and get sorted early. Because if we manage the biggest culprit is hypertension.. I believe if we manage hypertension well we will reduce the number of people who will eventually have heart failure.' (HP4)

Education of the community on HF was also proposed as a way to minimise stigma and discrimination and promote empathy. This is because they would be able to differentiate it from other illnesses.

'There is a plan actually to sensitise people because we realised people don't know. Even at school people keep on thinking but may be your child has something else - they usually they think of HIV.' (HP4)

Introducing screening for heart disease

Screening for heart disease was proposed as a means of preventing patients from presenting to hospital for the first time with advanced HF that was not amenable to medical treatment. They criticised the current health system for just being set to manage the very ill but failed to identify the earlier stages of the illness.

'I think it is more to do with our health system. Our health system for now is set to just fit those who are sick. You just have to get very sick for you to get people who can treat you. But I think if we had a system where we can pick up the people early you know we have a community setting where we pick up people with high blood pressure early before the heart gets damaged or my interest is rheumatic heart disease so if we can pick up these children early on before the valves get damaged because when they come here late there is nothing we can do. It's a structural disease, the patient are very sick, they just worsen but if we can carry out screening services, aah my view is that we should do it in the spectrum of non-communicable diseases so high blood pressure, diabetes, and rheumatic we can do echo screening and blood

pressure for people who are over 40. It would make a very big difference.' (HP3)

Improving follow up services and introducing community care for follow up

Health professionals suggested a public health approach to address issues of screening and early detection of the disease and to ensure follow up of patients, because lack of follow up led to poor adherence to treatment and recommended healthy lifestyles and ultimately progressive illness and repeated hospitalisation. The follow up of patients with HF is often challenging in Mulago Hospital, especially for those who come from outside Kampala because of challenges of having transport funds.

'I think the public health component of our treatment is lacking. Aaah Salt is a big social trigger of heart failure and so we educate them and say you know you shouldn't put table salt in your food. But because there is no one to follow up after a few days,….. We need to meet as stakeholders; doctors who are in cardiology, physicians, nurses, and then we look at both the in-hospital and the community. Community has two aspects,the screening bit and for those who already have heart disease as we discussed earlier on, we can follow them up, their nutrition, the salt issue and also make sure that they actually eat and as well taking the medication.' (HP3)

Health professionals argued that if there was a model of care that would involve community and home-based care borrowing from the HIV experience, it would improve patients' follow up and outcomes.

'Then we need an outreach program related to that such that once people are sorted then you can follow up because we don't have a follow up model. It is mainly in the HIV setting because sometimes you know we can reach them to their own homes and give them the drugs. If we are organised of course there are problems with numbers but if the different health centers were able to do the management and then they have a community person who is oriented they can check on those few who have not made it to hospital to see how they are such that before they are off drugs for two weeks someone picks that early and intervenes before a problem happens. Yeah..' (HP4)

'Um, I think we can do a lot, because most of our patients you realise they are really, most of them are on palliation. So I think we really need to kind of develop a way of following them up more better than the way we are doing, telling them to come back to hospital… sometimes I think of home based care for heart failure patients could help.' (HP7)

Investing in advanced treatments such as devices

To most health professionals, one of the most important things in improving care was to invest in devices which have been found to produce better outcomes in advanced HF as compared to medical treatments.

> *'I think the biggest thing is that the, in most cases the HF is really advanced. And you know these days the management of HF is more than just giving medical treatments it's really mechanical, resynchronisation therapy devices and things like that but in our setting we mainly use medical treatment. So even if a patient is adhering to treatment, they will always be back'. (HP7)*

They contended that since the majority of the patients presented at this stage the urgent way to improve care currently was to invest in this majority, some believed some of these may be curative for the patients.

> '*But also the other thing we also need to invest in these those who are at the end of the… and they need surgical…. they need devices, I think we need to invest in that because at the moment we have the majority of people lying the other side because if you don't „…… they will just die. They need other interventions that can may be curative. But medical treatments are basically supportive to delay symptoms and slow progression. (HP4)*

Developing social services

One of the biggest challenges and barriers in the care for these patients were the social issues, especially in those who were homeless. The health professionals recommended that there was need to develop and fund social services to assist those groups of patients and provide homes and ways to facilitate their personal growth. There was an appeal for having a home for the homeless.

> *'We are still struggling if we get funds we could start up a capacity building project so that such people like that woman get some income generating work to do after they leave hospital until when God decides. So the ones who are rejected it is a challenge when they have no where to go we have only one home for the abandoned owned by the nuns but it is always full, the nuns even no longer call me they used to call me when there were vacancies for abandoned patients. They used to come here every Tuesday when we got a case we would call them and they would come assess and then take the patient. There is need for a home those people with money if they could build a home for us as social workers it could help with those would do not have anyone.' (HP8)*

Summary

This chapter explored health professionals' understandings of patient needs, care required and service availability and their perspectives on what would constitute

better care and how this can be achieved. Health professionals described needs that fall in the standard categories of physical, psychological, social, information and spiritual needs. Their perceptions of patients' needs was derived from their experience caring for these patients and often they referred to patients they had been caring for when giving examples of the needs. Most of the needs health professionals mentioned seemed to originate from patients' beliefs and challenges in the health system.

From the health professionals' description of patients' physical needs, a theme that stood out was the differences in aims and expectations of treatment the health professionals and the patients had. Health professionals explained that there were areas of agreement but also areas of conflict in what the health professionals felt the patients needed and what the patients actually wanted from them. Health professionals felt that they needed to treat the advanced disease patients presented with, and improve their well-being, quality of life, and restore their ability to function. The patients' main concern was to feel better and emphasis was therefore placed on medications which made them 'feel good' but not on those which worked on the underlying problem. Health professionals described how sometimes patients expected and demanded for other treatments from the ones they were being given such as intravenous, fluids which from the health professionals' experience were not appropriate but the patients believed they would make them feel better.

Health professionals perceived patients' psychological needs as the following: the need for emotional support; the need for reassurance; the need for counselling; the need to address the issue of impotence; the need for security; and to be valued. They tended to give an explanation of the root of the psychological issues patients had and this was often related to a social problem that had resulted from having the illness.

Health professionals freely articulated what they perceived as patients' social needs, probably because the patients were most outspoken about them or because they directly affected care. According to them these needs included: the need for financial support and security; the need to be accepted in the community; the need to live a normal life; the need for nutritional support; and the need for support from their family and community.

Health professionals' views on patients' spiritual needs seemed to imply a general lack of awareness or understanding of these needs amongst the health professionals. Even after prompting on this need, only one health professional thought patients had spiritual needs, and the only spiritual need identified was the need to pray. Information needs included the need to give patients information on the prognosis of their illness, facts about the illness and on the recommended diet.

Health professionals described several medical and surgical services available to diagnose and treat physical problems associated with HF, which were provided in both inpatient and outpatient facilities and public and private settings. They described a lot of improvement in these services over the years exemplified by the introduction of medicines which improve mortality in HF and the use of mechanical devices in Mulago Hospital. This success however did not extend to lower level health facilities, which did not even have the basic diagnostic equipment or basic treatment for HF. There were also a lot of system failure issues in public settings that rendered these services not accessible to most patients. Services to meet information, psychological, social and spiritual needs were lagging behind those that were targeting physical problems in all health facilities and were very much in the embryonic stages as the biomedical model of care was still the predominant paradigm. Health system challenges (lack of medications and equipment, inadequate staffing, failure to provide information, failure to have multidisciplinary care) and patient related challenges (presenting with advanced disease, co-morbidity, poor adherence to treatment, inadequate self- care and lack of community support) were identified as barriers to the provision of good care.

Four main themes were identified from the health professionals' suggestions on how care could be improved and these dealt with issues of staffing, information, services and medications and equipment. These themes included: capacity building for health professionals; providing information to patients, their communities and the public; providing comprehensive services (which are multidimensional and also include prevention, screening, treatment, palliation and community care) and availing medications, equipment and devices for the diagnosis and treatment of HF.

CHAPTER NINE

9.0 Discussion

In this chapter, the methods and analysis used in this research will be reflected upon and discussed. The findings in chapters four to eight will be integrated and compared and contrasted. These findings will be discussed in relation to the existing research on heart disease and the theoretical literature.

9.1 Reflections on the methods

9.1.1 Strengths and limitations of the methods

There were several strengths and limitations in using an in-depth qualitative multi-perspective longitudinal approach.

Recruitment and retention

The process of recruitment proceeded successfully. What contributed to this was introducing myself to all the cardiology ward staff and presenting to them ethics and hospital administration clearance, along with a letter from the Deputy Executive Director of Mulago Hospital allowing me to conduct research in the hospital. I also explained my research to them and the grid of the criteria of the patients I intended to recruit. I shared a copy of my research proposal with the senior cardiologist at his request and he linked me to his research team. This research team was involved in another quantitative HF study and was therefore very helpful in identifying participants.

The ward in-charge put me in contact with the ward intern doctors and the senior house officers who were also informed of the patients I wished to recruit. When I appreciated how busy these health professionals were, I realised contacting them on the phone to find out if there were patients for recruitment was not possible. I worked out that the best way to get in touch with them was to go to the wards every day to find out if they had any patients who met the criteria I had given them. Initially I went to the wards every morning, but later I realised it was best after the ward rounds when they had assessed the patients for their suitability to take part in the interviews and when the patients' details were fresh in their minds, given that different cardiologists did ward rounds every day. The research team on the ward and the

intern doctors and senior house officers were particularly helpful because they were with the patients most of the time. The nurses tended to be too busy, and they only identified a few patients.

Most people were willing to participate in the study, probably because I had been introduced to them by their doctors and nurses. Building a relationship from the first interviews and also the monthly phone calls enabled retention of participants throughout the study. As a researcher, I had to observe high ethical standards to maintain relationships, but also to be humane and empathetic, which probably helped with getting consent for subsequent interviews.

The main weakness was with regards to retention as some patients could not be accessed on the phone for subsequent interviews. This could have been improved by getting more than one phone contact of their family carers. In Uganda, many people have mobile phones, but not desk phones and in this study only phone contacts of patients were obtained and once they died, or if their phone was lost, there were no other means of getting to them. So a few were lost to follow up, and it is not known if they had died.

Those who were not recruited

Those patients who had diminished mental capacity to give informed consent, those who were very ill with profound communication deficit, those who could not speak the two languages I speak, and those whose homes were more than 30 km from Kampala such that it would be difficult for me to follow them at home, were excluded from the study. I was dependent on the staff on the cardiology ward as gatekeepers and therefore it is likely that some eligible participants could have been missed out in the recruitment process, especially those who may have been involved in other research that was being led by the ward team. A significant number of patients could, therefore, have been excluded from participation in the study in the above ways and, therefore, their experiences and concerns underrepresented. If I were to improve on this in the future I would use an approach of interviewing a family carer as a proxy, to access these patients' experiences and concerns if the patients were able to give consent for that, especially those who are cognitively sound but have severe communication deficit, such as those who were extremely breathless to talk. In this

study a few patients had their interviews with their carers who tended to join the interviews as the patients got tired, and it worked out well as they were able to express their patients' experiences and concerns. Another way this study could have limited the problem of underrepresentation of those whose home address was very far from Kampala, hindering follow-up interviews, was to employ a flexible approach of using mobile phone interviews for subsequent interviews in geographically hard to reach areas. Other authors have demonstrated success with this approach (Sturges and Hanrahan, 2004. Smith, 2005). However, the challenge remains in how to best capture the views of those with diminished mental capacity and are unable to give consent.

Only five patients declined to take part in the study: three of them had participated in another study recently, where they had to answer too many questions and felt it was too much to go through another one. The other two declined outright without any reason. In these cases, their wishes were respected in line with good ethical conduct.

Multi-perspective interviews

By interviewing patients, family carers and the health professionals involved in their care we got a comprehensive understanding of the experience of living and dying of HF in patients in Uganda.

Individual and paired interviews

I set out to do all patient interviews as separate interviews because this thesis aimed at understanding the experience of patients. The intimacy of one-to-one interviews enabled the discussion of sensitive issues around diagnosis and prognosis and confidential issues, and also gave participants enough time to talk about their illness in detail freely. I was also flexible to allow paired patient and family carer interviews if patients wished their carers to be present or if they were too weak to undergo a lengthy interview. Some patients appeared nervous before the separate interviews started, but once we started, most participants talked freely about their experiences and most found the experience of the interview non-threatening. This was important in getting consent for the subsequent serial interviews. One weakness of the individual interviews was that sometimes patients struggled to remember their experience because they were tired, and there was no one to assist.

Three paired interviews were conducted as first interviews and in two of these interviews, participants had just been diagnosed with HF and were hospitalised for the first time. They asked that their family carers would be interviewed with them and since this was a challenging time for them I found it ethically appropriate to have a family carer with them. This nurtured a comfortable environment for those interviews. Therefore paired interviews had some advantages including: giving some participants more confidence to talk about some issues they would not feel comfortable to talk about if alone, especially health system issues, as observed by Morgan et al (2013); and it also gave insight into the relationship between patients and their families which has been observed in other research (Pinnock et al., 2011). Family carers sometimes gave vital information that was important to understanding the illness experience that the patients had not felt free to divulge or had forgotten to mention. Family carers mostly complemented patients' accounts; rarely did the two accounts differ.

Some disadvantages of paired interviews included: limiting the information given as in the case of one of the participants who was young and their family carer tended to protect her, and this may have influenced how much information she was able to give. Also one patient was interviewed in the presence of their partner and in this instance the account given without the partner about their concerns could have been different from that if the patient were alone, and there was a risk of breaching of confidentiality. In this instance, the patient showed me that he was taking anti-retroviral treatment for HIV, which he quickly hid away when his wife became involved in the interview. I suspected he had concealed this information from his wife, and this was an ethical dilemma for me because I wanted to get information regarding this but considering ethics regarding confidentiality, I did not inform the wife. I was able to get more information on his HIV during the following longitudinal serial interview that was done without the carer.

Use of in-depth individual interviews and paired interviews was a useful method for palliative care research that took into account both the patients' welfare and the objectives of the research. Family carers' views had to be cautiously considered in the analysis as their views of the patients' experiences though valid, may not always be a true reflection of what the patients experience (Addington-Hall and McPherson, 2001, Field et al., 1995)

Interviews with health professionals

The health professional interviews were important in comparing the ways the health professionals and the patients viewed the same condition, and their views gave a wider picture and understanding of the patients' experience. Health professionals' accounts were important in appreciating the services that were available for HF patients in the study setting that the patients had not mentioned because they were not aware of them. Health professionals also sometimes raised patients' needs and concerns from their experiences of working with patients that patients had not voiced in their interviews. It is possible that through their longer relationships with the patients they had built trust in which patients were able to tell them those things that were not told to me as an interviewer.

The health professional interviews were carried out after completing all patient interviews with the aim of getting them to react to some of the needs the patients mentioned in their interviews, and this worked out well. Individual health professional interviews were conducted for practical reasons as it is almost impossible to get the health professionals together at a given time for a focus group discussion due to their commitments in different areas at different times. However, focus group discussions would have been ideal for exploring and discussing issues on how care could be improved, how decisions are made by health professionals (Barbour, 2007) and in understanding the health system issues. Brainstorming in focus groups can help one person's ideas spark off other ideas making them suitable for exploring unanticipated ideas (Braun and Clarke, 2013).

Most health professionals were free to be interviewed but some were uncomfortable and probably thought it may be a test of their knowledge, especially since I had to record their voices, as identified in other studies, such as Coar and Sim (2006). One health professional after explaining to him that I would like to record the interview and guaranteeing to him that it would be confidential, was uncomfortable about it and often gave guarded responses, as observed by Chew-Graham, May and Perry (2002). Possibly I should have simply taken notes on this occasion. Sometimes responses given were steered towards teaching me rather than talking about the patients' experiences.

Longitudinal serial interviews

The longitudinal approach was very suitable for generating data that answered some of the objectives of this study, particularly in exploring needs and concerns of the patients which were dynamic over time, as demonstrated by previous research (Kendall et al., 2009. Murray et al., 2009. Calman, Brunton and Molassiotis, 2013). Monthly phone conversations were vital in identifying times of change in the health status of patients and served as triggers for conducting subsequent interviews to capture the changing experiences. Without these monthly phone calls, it would not have been possible in some patients to have longitudinal interviews because a significant number of patients died before the scheduled three monthly interviews. The other benefits of using a longitudinal approach were: the repeated contact with patients through phone calls and through interviews fostered relationships with patients which facilitated discussion of sensitive issues and access to patients' private accounts (Murray et al., 2009. Pinnock et al., 2011) and made it easier to get consent for subsequent interviews; the opportunity to explore in detail those issues which were not very clear in the first interview in subsequent interviews; and, the opportunity to conduct the interviews in different settings, that is in the hospital and in patients' homes, and this helped in interpreting the findings of the research in the different contexts of the interview. Whereas in the first interview most of the accounts given were retrospective, subsequent interviews were useful in exploring experiences as they happened and, therefore, reduced chances of challenges of recall.

The longitudinal approach, however, had challenges, and these included: generating a large volume of data for analysis and this required good planning and spacing of interviews; and, challenges of attrition because many participants died before they could complete their three interviews. This study tried to offset this by doing bereavement interviews with carers to get a picture of the experience of dying. The other challenge was it was hard to access some patients and their carers on the phone despite repeated attempts and no clear addresses. In retrospect, this could have been improved by arranging to go with the patients to their homes to establish their home address, and by getting more than one phone contact from their relatives. It was difficult to determine the intervals at which to do the serial interviews because there was not much data to suggest when most deaths happened after discharge of HF patients in the Ugandan setting at the time the study was done.

Use of a checklist

The use of qualitative interviews coupled with a validated checklist (The APCA African POS and the POS-S), gave a comprehensive view of the symptoms patients with HF have. These two methods were found to be complementary and the APCA African POS and POS-S added value in the following ways: in illuminating symptoms not mentioned in the qualitative interviews and revealing how severe they were as this was not sometimes mentioned in the interviews. The APCA African POS and POS-S were especially helpful in identifying more physical symptoms and spiritual problems, whereas the qualitative interviews worked out better for identifying the psychosocial issues.

This finding of the combination of qualitative interviews with a checklist to provide a comprehensive symptom experience is consistent with the findings by Anderson et al. (2001). The POS in this study was not used as a means of getting quantitative data so as to find statistical significance and association but was used for merely descriptive purposes to give a broader understanding of the experience so that the study could be clinically relevant, and the patients could be situated in a wider group of people at the end of life. No sample size calculations or tests of significance were done: the figures were used descriptively, and some authors consider this an acceptable approach in basic exploratory research such as this (Onwuegbuzie and Collins, 2007).

9.1.2 Reflexivity – positioning of self in the study and how it may influence the data

Throughout this research I found it important to be reflexive about the research process and my position in the research, as it had an impact on the study participants, the questions being asked, data being collected and its interpretation (Berger, 2015). I did this by keeping a journal. My background is as a palliative care doctor in Uganda and I came to do this research because I want to establish palliative care services for patients with HF in Uganda and need an evidence base for clinicians and policy makers before I can influence the current situation, which is that palliative care is mainly for those with cancer and HIV/ AIDS.

I had to be reflexive about the different roles I had during the research, that is my role as a student researcher, my role as a doctor and my role as a woman doing research with both men and women in a culture sensitive to gender roles. These roles influenced the questions I asked and how I analysed and interpreted my research

findings. I informed the participants of my role as a research student but did not come outright to tell them I was a doctor unless they asked me, it is then that I told them I was a doctor but emphasised that at that moment I was a student not working as a doctor. Richards and Emslie (2000) found that patients' knowledge of the researcher's background will influence responses given. Therefore by not disclosing my role as a doctor, and by distancing myself from the health care system, I hoped that I would be able to get genuine accounts of the experiences of the health system and that I would be able to get responses that were not only bio-medicine related. Although I did not explicitly talk of my role as a doctor, I realised that I was perceived as affiliated with the health care system having being introduced to them by the ward health professionals and this could have influenced accounts from the patients.

In some instances being female interviewing male patients could have influenced the information they gave me, especially about sensitive cultural issues of sex that I found from the health professionals' interviews as significant issues that male patients talked to them about, but none of the male patients I interviewed talked about. Female patients equally did not talk about sexual issues, a finding I expected because the side-effects of HF medicines that affect sexual performance are more common in men. This finding of the influence of gender on interviews is consistent with the findings of Williams and Heikes (1993). The patients' accounts were also influenced by the social context within which they were constructed, for example one patient was more confident to express her dissatisfaction with the health system when interviewed at home but had reported having no problem with it when interviewed in hospital.

I found several challenges as a palliative care doctor doing qualitative research among patients who needed palliative care and were not getting it. It is during these times that my role as a student researcher sometimes conflicted with my role as a doctor. The conflicts arose because as a researcher I wanted to advance knowledge on the subject I was studying by using rigorous methods .To ensure rigorous methods, I wanted patients to see me as a researcher so that they disclose to me as much information as possible that they would not give a health professional for fear of sanctions and I also wanted to avoid giving any intervention that would interfere with the research findings. However, as a doctor who has been socialized into the ethics and values of the profession and has moral obligations to the sick, I had to keep the

welfare of the patients and medical ethics in mind by showing empathy and ensuring beneficence and respect and by not using people as means to an end. Moreover, patients could not understand the difference in roles, to them doing researching on a health topic probably meant I was a health professional and they expected from me care and information on their illness and not being able to help them because of my role boundaries made me feel awkward and sometimes guilty because they had given me their life stories and I felt obliged to give back by helping medically. It therefore required from me constant deliberate effort to not be a doctor, particularly when I noted areas that were not well managed well, such as symptoms that were not controlled or unresolved spiritual of psychological issues that I was more knowledgeable in their management (because of my extra training in palliative care) than the other health professionals on that ward. After having debriefing sessions with my local supervisor a decision was made to inform the ward team, so that they could facilitate a referral to the palliative care team in such situations or that they would give patients information about services in the community that could be of help. I was also asked many questions by the participants who greatly lacked information about their condition and being aware that answering or not answering them would influence the interview, I differed the questions to the end of the interview and then with the patients' permission I informed their health professionals of their needs. This was a process recommended by Jack (2008). However, I still felt unsatisfied wondering if the need would be attended to given how busy the wards were and how few the health professionals were. What complicated my decisions more was the fact that there is no consensus in the current literature on the health professional-researcher role boundaries when conducting research in clinical areas (Wilkes and Beale 2005). Some principles of ensuring rigorous research contradict those of medical care. For example Fowler (1988) argues that the nurse researcher though dedicated to research remains dedicated to the patient first and that ethical obligations as a nurse come first before needs of research . On the other hand, researchers are asked to eliminate personal feelings such as empathy from research to be objective and objectivity and empathy seem to be contradictory, but empathy is a core value in medical care (Wilkes and Beale 2005. Holloway and Wheeler 1995). One area of common agreement is that a researcher with dual roles as a clinician and researcher can be involved in intervention in cases of life-threatening situation or in

extreme anxiety, (Wilkes and Beale 2005) and I applied this principle during this research.

Another area of challenge was during the process of interviewing; both the researcher role and the medical role involve interviewing of people but the interviews have different objectives. In the medical role the interview is aimed at assessing the illness and in the researcher role it is aimed at answering research objectives. Having had more experience as a doctor than a researcher interviewing as a means of assessment comes more naturally and I had to re-orient myself all the time to keep the research objectives in mind and not the disease process and I had to learn to see people as research participants not patients. As a researcher I also had difficulty in deciding the appropriate relationship to have with the patients; whether it should be a relationship of non-disclosure and holding back or one of self-disclosure. The literature on this is conflicting with some researchers advocating for the role of a researcher as investigational not an educator or counsellor to avoid bias (Holloway and Wheeler 1995) however other researchers from their experience felt this was dishonest and unnatural and can hamper the research relationship once participants see through it. They therefore argue for an open relationship but advise the researcher to be reflexive on its impact on the research. (Colbourne and Sque, 2004) I settled for reavealing my role as a doctor if and when patients asked me if I was a doctor, as a middle ground between these postions and debates.

Role conflict has been noted in several studies done by health professionals, and it was useful to apply some of their approaches to this issue in my research (Jack, 2008. Colbourne and Sque, 2004). I was anxious about the interviews in the beginning because I had been involved in a qualitative study before in Uganda and participants had not felt free to share their experiences, and they had given very brief responses and I thought it would be the same this time. My first participant shared freely but the second participant was very brief and when I listened to the interview afterwards, I realised that for this one I came in quickly with another question to bridge the silence and reflecting on this in my supervision meeting, and with peers, I decided to be more relaxed and open-minded. Most of the little research experience I had prior to this study was underpinned by a positivist epistemology and, therefore, this could have influenced the way I initially formulated and administered the interview guide and my initial interviews may have been more shallow.

9.1.3 Ethical issues of conducting research in vulnerable populations

In this study, special attention was given to the comfort and welfare of the patients. It was emphasised to the participants that they were free to stop the interview at any time if they did not want to continue and to opt out at any stage of the interview. Participants were informed that there were no direct benefits for them in taking part in the interviews. I was aware of the possibility of research fatigue and the potential for the research to cause distress (Casarett and Karlawish, 2000) and measures for referral were put in place for those who were distressed. Throughout the interviews, cues for distress were searched for, and interviews were stopped when deemed to cause distress. In cases of newly diagnosed patients and patients who were at risk of fatigue because of their advanced medical condition, family carers were encouraged to be present during the interview and they often took over the interview when the patient was tired. One young patient when recalling her experience and social problems became distressed and was referred to the palliative care team for psychological support after informing the ward team. Some participants expressed some benefits of participating in the research as a chance to talk through their lives and being listened to in line with the findings of Gysels, Shipman and Higginson (2008) and many were neutral to it.

9.2 Analysis

9.2.1 Managing data

The serial qualitative interviews yielded large amounts of data and much time was spent coding and analysing the data. With this volume of data, there was a risk of not going into depth in the analysis. Employing the techniques of line-by-line coding followed by focused coding and theoretical coding, facilitated in-depth analysis along with discussing the analysis process and outcomes of the analysis at different stages of the analysis with my supervisors and with peers, enabled me to focus and to direct the analysis to the study aims and objectives.

9.2.2 Using the constant comparison method

The constant comparison method was employed in analysing the longitudinal data. This method was complex and time consuming. Constant comparison of data was

done for the interviews with the same participant over time ('case profile') and this helped in tracking changes and continuities over time and in understanding each person better (Thomson and Holland, 2003). Constant comparison across all interviews helped highlight differences and similarities within the sample and enabled comparison based on a range of factors. Use of both the 'case-profile' and cross-sectional approach facilitated a comprehensive understanding of the results but was labour intensive as found in other research (Thomson and Holland, 2003). In my analysis plan before the interviews I intended to first look at the participants' data in a cross-section to compare emerging themes across the two age groups where HF is clustered in Uganda (the young and the old) but after analysis it emerged that there were not many differences between the two groups, and, therefore, the groups were analysed together. Key themes across the group were identified 'at moments in time which focused on biographically structured temporal themes', an approach used by Thomson and Holland (2003) and I mapped how these themes developed for the group over time.

9.2.3 Analysis of the APCA African POS and the POS-S

The APCA African POS and the POS-S were used to see if it could add any details and breadth to the holistic experience and to map changes, if any, in the multidimensional experience of the patients. Simple descriptive statistics were used for its analysis by using mean POS scores for each item across the three interviews. The POS tools were useful in identifying those issues that participants had but had not spoken about in their qualitative interviews and to determine how distressing these were to them, again a factor that had not been obvious in the qualitative interviews. Being done after each in-depth interview, it allowed us to assess how good the POS was at capturing data, using the in-depth qualitative interview as a "gold standard."

9.2.4 Translation into practice and generalisability

'*Qualitative research makes significant contributions to evidence-based practice by generation of hypotheses; development and validation of instruments; provision of context for evaluation; development of acceptability of interventions; development of new research questions; and application of Qualitative Outcome Analysis*.' (Ailinger, 2003, p275). Qualitative research is also important in the different stages of policy making. Ritchie and Spencer (2002) described the types of qualitative approaches that

can contribute to policy and these include: contextual research that '*describes phenomena as experienced by people and how they are understood by them'; 'explanatory research which explains why phenomena occur and the forces that drive their occurrence'; 'evaluative research which is concerned with how well does it work (processes and outcomes) a question central to policy; and generative research, which is concerned with producing new ideas such as hypotheses or solutions to problems*' (Ritchie and Spencer, 2002. Lewis and Ritchie, 2003).

This research has provided evidence of both a contextual and explanatory nature for policy and has contributed to evidence-based practice by identifying patients' needs and how care can be improved. This information will be summarised for ease of dissemination and will be written in a way that will be accessible for public policy and clinical practice. Evidence-based practice often requires generalisability. Qualitative research by nature is not statistically generalizable, but Lewis and Ritchie (2003) have identified three types of generalisability in qualitative research. These include: *representational generalisability* that is whether what is found in a research sample can be generalised to the parent population where the sample was drawn; *inferential generalisation* whether the findings can be generalised to other settings; and, *theoretical generalisation* which draws theoretical principles from the findings of a study for general application (Lewis and Ritchie, 2003). The data from this study combined with other existing research and theory can contribute to theoretical generalisation. Representational generalisation for this study was ensured by the use of rigorous methods of data generation and analysis to enhance the validity and reliability of our research methods (Lewis and Ritchie, 2003).

9.3 Summary of the findings

This study aimed to understand the multidimensional needs and experiences of Ugandan patients with advanced HF over the course of their illness. The main themes included: the symptom experience, its impact on functioning and the need to return to a functioning self; health illiteracy and the need for information; culture and lay beliefs and knowledge; health system challenges; the illness impact on the daily lives of the patients; coping and adaptation; poverty; dying of HF; the need to find

meaning; health professional-patient relationships; the services available; and, health professional perceived needs for patients versus patients' reported needs.
An overarching theme in the illness experience was that of living with the unknown. These themes will be discussed below in light of existing research and theory.

9.4 Integration and reflection on findings, existing research and theory

9.4.1 The symptom experience

The burden, nature and course of symptoms

Participants in this study reported having cardiovascular and non-cardiovascular symptoms, and both were causing significant distress. This finding is important for clinicians to be aware of because it was observed from the health professionals' interviews that they only mentioned symptoms related to the cardiovascular system when asked about the physical problems. This may mean that non-cardiovascular symptoms are not being identified and therefore not managed, as observed in previous research (Walke et al., 2007b). It was also observed that over the illness course the prevalence of some symptoms remained near the same despite treatment (Table 7) and in some cases the severity of symptoms did not improve or even worsened as illustrated by the mean POS scores in table 8. This was more common in the symptoms not typically related to the cardiovascular system than those in the cardiovascular system. This finding is similar to the findings of other researchers such as Walke et al., 2007b and Albert et al., 2010. The possible explanations for this could be that treatment was targeted at the disease, not the symptoms as medical training in Uganda currently emphasises treating the cause and rarely symptoms. An additional explanation was poor adherence to treatment because of lack of medicines that was a common problem in the setting. With the current emphasis on patient centred care there is need to pay attention to causes of distress amongst patients alongside treating the disease, especially in the light of evidence suggesting that symptoms have prognostic significance in HF (Ekman et al., 2005). Lack of explanation from health professionals about the illness might have also hindered symptom control as a lack of understanding and anxiety can prolong suffering.

Symptoms and participants' definition of illness

This study found that the presence of symptoms in itself did not equate to being ill, and often symptoms were explained away as being due to fatigue, old age, co-morbidity, and common "minor" self- limiting sicknesses. It was not until the symptom experience was significant to the patients that it was deemed as illness. A 'significant symptom experience' included the following: being unable to work, symptoms legitimised by others in the community as due to illness (such as swelling), symptoms associated with feared medical conditions in the community (such as tuberculosis), and symptoms not amenable to local herbs and remedies. Only when the symptoms were recognised as illness was medical care sought. These findings are consistent with the findings of Dixit, Mishra and Sharma (2008) who found that in India the Bondos tribe defined illness as being unable to work, feeling weak and being non-functional and health as being able to carry out social roles. The social-economic conditions of these people were similar to that of those in this study's population and may explain the similar findings. In Uganda and in India, where survival is dependent on work, illness may need to be put off until one is non-functional because of the need to continue to work. These findings also fit into Kleinman, Eisenberg and Good's illness explanatory model (2006) that illustrates that labelling of one's changed body feelings (symptoms) by one's self or one's family as illness is important in defining illness, and this will depend on the patient, family and community's perceptions and evaluation of these bodily changes and how they explain illness. They argue that disease (*'abnormal psychophysiological function'*) should be differentiated from illness (*'personal, interpersonal and cultural reactions to discomfort or disease'*) as illness is a cultural construct (Kleinman, Eisenberg and Good, 2006, p141). They go on to explain that health professionals view the disease as the problem, and patients the difficulties in living due to the sickness that is the illness. Bury (1991) also explains that people test the meaning attached to their bodily changes with their experiences with others first because they are not sure if they will have shared perceptions of the same situation as others. Bury (1991) and Kleimann, Eisenberg and Good's (2006) theories, therefore, explain delays in defining illness in our study because of the need for legitimacy and cultural definitions of illness. These are significant messages for health educators and health professionals to understand because patients' definition of illness impacts when care is sought and will determine if one continues with their treatment or not.

The symptoms course and impact on participants' lives

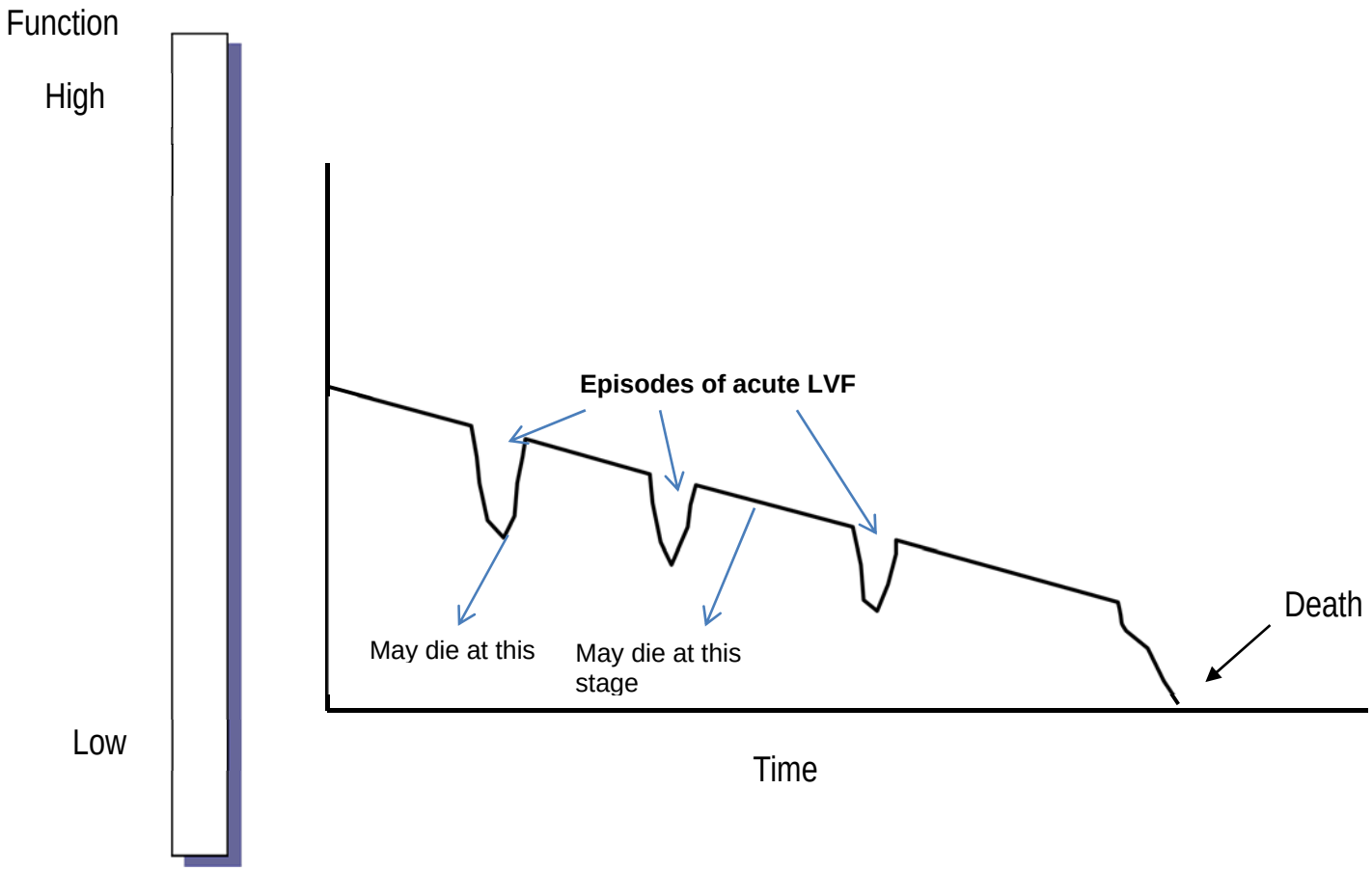
The symptoms had a profound impact on the participants' physical functional status, which mirrored the symptom course - a finding that is present in the literature. (Walke et al., 2007a. Song et al., 2006). Three trajectories of functional decline were identified in HF patients on treatment. The first was that of an excellent initial response to treatment and return to near normal function and a period of stability followed later by recurrence of symptoms and progressive decline in function interspersed with periods of wellness and some improvements in the level of function and gradually ending in a state of intractable symptoms and dependency, then death. The second was that of an initial period of no improvement on treatment and very poor performance status later followed by gradual improvement in symptoms and return to a reasonable level of function, followed by periods of wellness interspersed by periods of gradual decline, until they ended in a state of intractable symptoms and dependency and death. Finally a trajectory where there were intractable symptoms and continued and rapid decline in function to dependency from diagnosis to death, akin to the acute decline described in the classical "cancer trajectory".

Most previous research has described a typical trajectory of functional decline for those with organ failure (Lunney et al., 2003, Murray et al., 2005). The first trajectory described above in this study is similar to the typical organ failure trajectory described in the above previous studies but the other two are not. The reason for the two being different could be that this study was limited in getting a full understanding of the pattern of decline because participants in this study were only followed up for six months and, therefore, there were not enough longitudinal interviews to observe their trajectories. Additionally the interviews were initiated at different points in their illness trajectories, and I would argue that these two different trajectories illustrated in this study represent part of the typical trajectory described for organ failure but what we observed was people starting at different points on this trajectory as demonstrated in figure 6 below. However, it is possible that these trajectories are giving a true representation of the functional decline in the Uganda setting that could be different from the typical one seen elsewhere, due to the different circumstances in which the research was done. Most previous research on trajectories of decline has been done in high-income countries where patients present relatively earlier for treatment and where there are no challenges in accessing medicines. Therefore the course of symptoms and functional decline could have been influenced in this study by the

extent of structural damage to the heart Ugandan patients had before they presented, as they presented with advanced disease, the inconsistent availability of medicines for HF, especially those medicines which offer mortality benefit and improve the structural changes in the heart, and the inconsistent level of professional and self-care given due to poor follow-up.

To my knowledge, this is the first qualitative study to describe the symptom course in patients with HF in Uganda drawing on both the retrospective and prospective accounts of patients and has raised questions for further research. Further longitudinal research, both qualitative and quantitative, following more patients over a longer time and with more serial interviews is needed in the Ugandan setting to give a clear picture of the pattern of functional decline in these patients.

Figure 6: Trajectory of physical decline in HF in Uganda



Need to return to normal function

For all participants, the major physical need was to return to normal function and to prevent death. Some even expected cure initially, but as the illness progressed their expectations changed to the need to be comfortable and perform important roles in their lives. Younger patients and those who had lived with the illness for less than a year had more expectations from treatment. Similar findings of change in expectations have been found in the work of Bury (1991). This change in expectations could have been influenced by the experiences of the treatment and the illness being one that recurs, observations of their peers and from acquiring information about their condition.

9.4.2 Health illiteracy

A major finding in this study was the very low level of health literacy amongst the patients. Most patients in this study had only up to a primary level of education and this may explain the low health literacy levels that have been found to correlate with literacy levels below that of high school (Peterson et al., 2011). There is a paucity of data on health literacy in Africa, but the available data is consistent with findings of very low health literacy (Atulomah and Atulomah, 2012). Many patients did not even have knowledge of the kind of diet they needed especially regarding the use of salt and water. This should be a major public health concern because in HF low health literacy has been shown to be a barrier to self-care and is associated with increased mortality (Peterson et al., 2011).

Health illiteracy was a major contributor to the late recognition of illness, late seeking of health care and a determiner of where care was sought, as patients' understanding of their illness was based on the level of health literacy. Limited understanding of the illness led to assuming wrong causes of the illness and seeking care in unconventional areas. The emotional response to diagnosis was also partly influenced by participants' level of health literacy. Health illiteracy also was a factor in the improper use and sometimes abandonment and the refusal of medicines (such as oxygen) prescribed for the HF, misinterpretation of health information given and inappropriate self-care. The finding of health illiteracy being related to poor treatment adherence and poor self-care has been observed in the literature (DeWalt et al., 2004. Liu et al., 2014).

At the community level, health illiteracy led to stigmatisation of those with an unknown illness, a finding that has been found in other illness such as mental illnesses (Hocking, 2003).

Need for information

The need for information was one of the commonest needs expressed by patients and professionals. This may reflect that services have not been addressing this need well, as confirmed by the health professionals' interviews. A lot of information was also needed from health professionals because in the study setting lay people were more familiar with communicable diseases which are reversible, and therefore this was a condition that was difficult for them to conceptualise and access to information sources such as the internet or books was limited. Information was needed so as to understand the meaning of the symptoms, the cause of the illness, the tests done, the prognosis, the roles of the medicines, how to care for self and to explain to their communities, since their condition was an unfamiliar condition with the potential for causing stigma.

The underlying need for information I would argue was the need to regain control over their lives which they felt were now unpredictable and to allay anxiety findings that were also described by Williams and Koocher (1998). Most information was needed at the stage of diagnosis probably because of the high anxiety levels associated with this stage and also when on treatment, especially when the treatment was not causing much improvement, leading to anxiety. Preference for timing of giving information at diagnosis has also been observed by Caldwell, Arthur and Demers (2007). This is an important observation for health professionals as they work with patients, to know when interventions with information should be timed. Most health professionals reported giving information but acknowledged that sometimes it was not enough because of the short consultation times. When information was given it was often not understood by patients and was confusing because there were no consistent information sources. This led to patients creating their own body of information that was intelligible to them by drawing on the little information they had received from the health professionals and lay perspectives to make sense of what was going on. These findings are consistent with Williams theory of narrative reconstruction (1984) that Bury (1991) further elucidates on, that people will make up

narratives of their illness that make sense to them in 'an attempt to create order out of a fragmented life. ' This highlights the need for information that is consistent and more accessible to the population with low literacy.

9.4.3 Culture and Lay beliefs

Culture and lay beliefs influenced the experience of patients with HF by their impact on health behaviour. Health illiteracy, culture and lay beliefs were closely related. Where there were deficits in health knowledge the cultural beliefs, lay beliefs and narratives often filled in the gaps. For example, cultural beliefs and lay narratives were used by many patients to explain their symptoms, define illness (as explained above), the illness cause, the diagnosis, which medicines were appropriate for use and which were not, how to care for self and the prognosis of their condition. Cultural and lay beliefs on illness often differed from biomedical ones and sometimes lay beliefs incorporated medical knowledge. For example, many patients believed their illness could have been caused by divine causes, imbalances in the body and curses from others, and therefore sought traditional cultural care but at the same time they thought that it could be a biomedical cause and sought care in hospital. Almost all patients had either used traditional herbs or consulted with a traditional healer following advice from other lay people, and they often referred to the advice from these alternative practitioners signifying how dominant this paradigm on what causes illness is, in this population.

This influence of lay beliefs on health behaviour was dominant probably because they sounded more intelligible to the patients and also because the lay beliefs were the pervading ideas in the public arena. As Sabuni (2007) explains, people are socialised into these cultural ideas of health and illness since childhood and therefore it is easier to comprehend these ideas than the biomedical ones. Also the Ugandan culture is mainly an oral culture (given low literacy levels) and reading or research on particular issues such as health is for the very few. Even the literate get most of their information from the media. The traditional healers and alternative practitioners have been aggressive in the use of media, especially the radio, which is the media most commonly used (unlike medical practitioners). Their information tends to appeal to the people because it is more concordant with what they know (Astin, 1998) and relates to their discomfort directly and they emphasise explanation of the illness as opposed to disease and as explained by Kleinman, Eisenberg and Good (2006), this

has contributed to why people increasingly choose to go to alternative practitioners. This has important implications for the training of health professionals in the approach to care of these patients.

9.4.4 Health system challenges

Although late presentation to health care was common, limitation in the health system from primary care to the national referral centre contributed to negative illness experiences in the following ways: late diagnosis because of lack of diagnostics both basic and advanced; poor control of symptoms because of a lack of medicines; poor quality of follow-up care due to overwhelmed services; poor self-care due to insufficient services for the provision of information; and inadequate social and psychological care because of lack of recognition of need of these services. Most research on the illness experiences of patients with HF has been in developed countries with relatively well-functioning health systems, and these findings are therefore different from previous studies. Therefore, this study illuminates the experience of living with HF in a poorly functioning health system as an addition to the illness HF experience literature.

The health system in most of Africa is plagued by lack of funding, for example very few countries have met the Abuja Declaration of 2001 target of allocating 15% of its GDP to health (Sambo, Kirigia and Orem, 2013) and this has led to poorly resourced public health facilities with regards to human resource, treatments and equipment for diagnosis and treatment. This has been observed in a systematic review of health systems in low and middle-income countries (Basu et al., 2012). In addition, due to different socio-economic, political and environmental factors, brain drain has contributed to worsening the already struggling health professional patient ratios (Kalipeni, Semu and Mbilizi, 2012). In lower health centres, which patients access easily, the health care professionals often leave to replace those in urban areas who have migrated to other countries (Kalipeni Semu and Mbilizi, 2012) leaving health care workers of low grade training who ideally would not be working independently, but due to the lack of appropriately trained health professionals they have to manage the centres. To further aggravate the situation, the centres are very busy, so these health care workers do not have time to engage in continuous professional development. The health system in Uganda was mainly designed to manage acute conditions and now with the dual epidemic of non-communicable and communicable

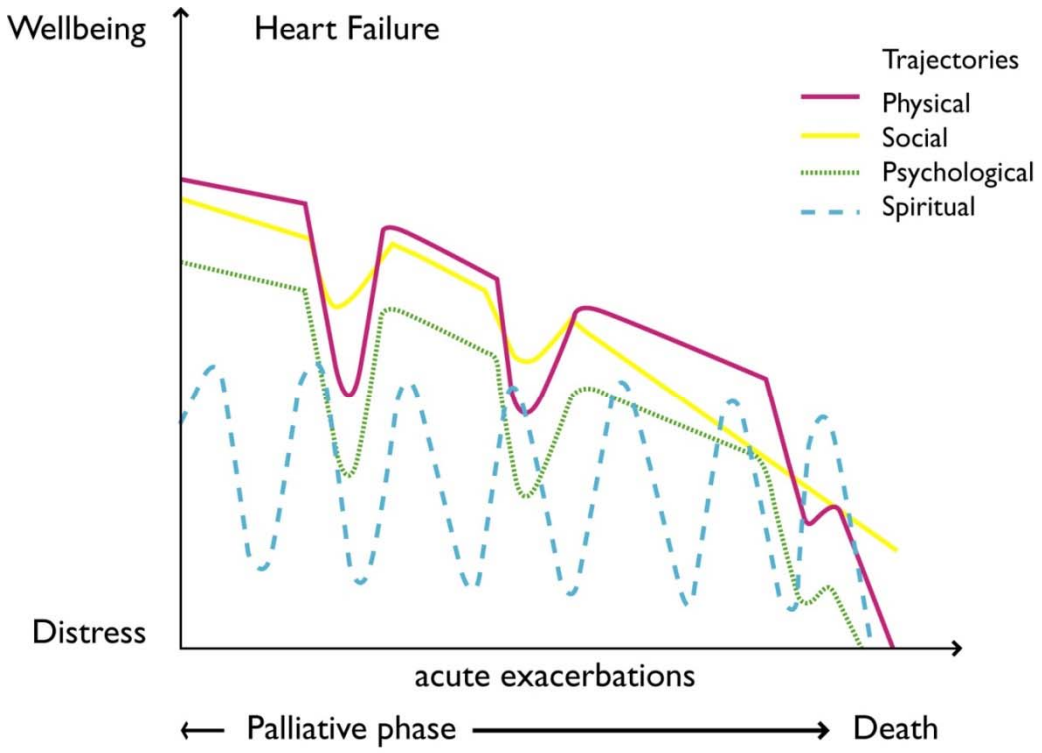
disease, there is need to rethink the system, especially with regards to chronic disease management including holistic care and good follow up care. A lot of lessons have been learned in HIV care that could be transferable to HF, and these need to be employed (Chalker et al., 2013. van Olmen et al., 2012). These findings, therefore, highlight important implications for strengthening primary care, district hospitals and referral and discharge.

9.4.5 Impact of the illness on the daily lives of patients

The impact of illness on patients was multidimensional impacting across the physical, psychological, social and spiritual domains. This finding links to that of previous research by Boyd et al. in 2004, and Ryan and Farrelly in 2009. The physical impact was described by patients in terms of the various symptoms they experienced and their reducing level of function. Psychologically the illness led to emotional pain characterised by anxiety, worry, anger and depression. These were precipitated by the fear of death, the experience of loss, an uncertain future and an anticipation of being isolated. These are also consistent with the findings of Bosworth et al. in 2004. Patients described being worried more often and more vividly and severely in the first interview and the last of the three interviews. This could be attributed to the fact that the first and almost all of the last interviews were done in hospital when the patients had acute exacerbations, and they were, therefore, more anxious. Also for many patients by the time their third interview was being conducted (12-24 weeks after the first), their functional status had greatly deteriorated, and the continual decline in their health led many to feel despair. This resonates with findings of Murray et al. (2007) who found that psychological distress mirrors physical decline as represented in the graph below.

Figure 7: Trajectory of physical,social, psychological and social well-being in HF patients

(Murray et al. 2007)



Within the spiritual domain, some participants experienced spiritual suffering and pain while others described spiritual growth. Spiritual suffering and pain resulted from the feeling of being rejected by God, feeling valueless and feeling guilty over past behaviour. Spiritual pain and suffering such as this has been noted in HF and other life-limiting illness as patients try to make sense of their illness and to find meaning (Grant et al., 2004. Ross and Austin, 2015). One reason for this despair may be linked to a commonly held religious belief in Uganda and across East Africa, that suggests all illness is orchestrated by a Divine power(s) as a punishment or as a test, while others who hoped for healing in God and trusted God as the great healer were disappointed that God had allowed the illness into their lives. This view is similar to that found in patients with other life-limiting illness in South Africa (Mabena and Moodley, 2012).

Although most patients said they felt some degree of peace, for almost half of the patients, this was rated as very low, and over half felt no peace at all. This may be associated with their psychological distress over their illness, their lack of

understanding or their sense of spiritual suffering (Steinhauser et al., 2006. Murray et al., 2007), yet despite this low sense of peace, all patients felt life was worthwhile even in the midst of their suffering, and most rated their life worth highly with very few rating it as low. One patient felt that even though she was completely dependent on others her life was still of value because she could still offer useful advice to her children. This sense of value may be tied to the community views on the worth of life. Some patients experienced spiritual growth despite the suffering and this led to stronger faith in God, increased patience and developing an attitude of gratitude as expressed by one patient 'finding the good in the bad', findings similar to those from other African settings (Mabena and Moodley, 2012).

In the social dimension participants faced rejection, stigma and isolation because of the following: the community fearing catching the disease; failing to meet social roles especially women spouses who could not meet their husbands' demands; and, when they became very dependent that they could not attend social activities. Social isolation and being discredited in chronic illness is widely recognised in previous research (Charmaz, 1983). Rejection and isolation of women because they failed to meet social roles can be explained by the culture in this setting, where women are obliged to meet some roles and failure to do so renders them not important in the home. Also, men are not so much expected to do the caring role when their spouse is ill, it is done more by her relatives or in-laws. Employees were told to stop working (without compensation) by their employers because they were always off sick or were not as productive as before. However in some cases relationships were strengthened, especially between parents and children. These findings resonate with Bury's theory of biographical disruption where he explains that chronic illness brings an individual, their family and social network, face-to-face with the character of their relationship as normal rules of reciprocity, and mutual support are disrupted (Bury, 1982). These findings of the multidimensional impact of HF have implications for care, training, government policy and health education. Care should be multidimensional which is a practice embraced in palliative care, training should be based on a wider model than the current biomedical model, and also in national employment policies there should be considerations for those with chronic illnesses and disability. Health education for the public should address the social stigma and isolation issues and the need for social support in these patients.

9.4.6 Coping and Adaptation

Participants' psychological needs and social needs were steered towards the need for coping and to adapt to changed circumstances in their lives. They employed cognitive and practical ways to be able to live with the illness and the suffering associated with it. Participants employed different coping mechanisms because of the differences in their personalities, previous experiences, belief system and their social context findings that resonate with those in a systematic review by Li and Shun (2015). Hope was central in most of the mechanisms employed in coping by these participants. The relationship between hope and coping in chronic illness has also been described in the literature e.g. by Herth (1988). Coping mechanisms employed included faith in God and surrendering to Him, sharing problems with others, comparing themselves with those in a worse situation, practicing an attitude of gratitude, reference to inspiring stories of courage, hope and faith, acting stoically, letting go, avoidance, destruction, denial , bargaining and accepting the inevitable, echoing findings in previous studies (Bosworth et al., 2004. Boyd et al., 2004. Seah et al., 2015,). Coping ability generally increased over the illness. Faith-based coping seemed to be more sustainable throughout the illness than coping based on hope of improvement in functional status and by denial and bargaining. The most commonly employed method was surrendering to God, which reflects the highly religious community. Most participants employed more than one coping mechanism. Further research is needed to find what coping mechanisms are more useful and which should be encouraged.

Participants had to adapt to a new life of disability, being on chronic medications, and attending health facilities for chronic care. Adaptation included managing treatments and their environment and self-care. The managing of treatment involved physical, social and psychological work. Physical work involved pragmatic taking of medicines so that their side-effects would not manifest in public, social work involved selling off their assets so as to get funds for treatments, and psychological work involved accepting treatment as part of their lives and putting it into their daily schedules. The environment had to be manipulated in the best way possible for the patients by their family carers so that they would remain functional for as long as they could. All participants wanted to do something to participate in their care, probably because this

was a means of getting control of their situation. These findings are in line with Bury's theory (1991) that described mechanisms of adaptation used in chronic illness including managing the manipulation of resources, mobilising resources, managing treatment and setting realist goals as 'strategies' used by people to adapt. Findings of management of treatment being considered as work were consistent with the 'treatment work' described in chronic illness by Strauss et al. (1982) who also described the work involved in managing treatment.

9.4.7 Poverty

Poverty pervaded the lives of most patients and impacted on their experience. Most patients were low earners and loss of work for them and their family carers, having to pay for medications, exacerbated the poverty leading to being trapped in a worsening cycle of poverty. It is estimated that 37.9 % of Ugandans live on less than 1.25 USD a day (World Bank, 2015). Poverty exacerbated the illness experience. It contributed to worsening the symptom experience because patients had no money to go to hospital for diagnostic tests and treatment or to buy medications when they were not available in the hospital. Some symptoms were also due to poor nutrition because of no money for food. Other areas poverty impacted were: late seeking of care; coping and adaptation because resources were not available to improve their ability to function; and, the social and psychological experience because ill people were not allowed to be ill, they had to work for their own and their family's survival and had to meet particular roles in community. Poverty at the country level led to poor resources, lack of services in the health care facilities and low health illiteracy. Low health literacy has been found to be associated with low general literacy rates in the country which also reflects poverty as observed by other authors (Beaglehole et al., 2011). This finding of poverty and its impact has implications for chronic disease management as most people cannot sustain their treatment out of pocket, and although there is a big campaign to educate people about the prevention of HF, chronic disease care plans have to minimise the repetitive cycle of poverty and illness by improving free drug availability and supplies in health centres, because one ill patient with HF means more than one person out of work (including the family carer) and this in turn affects government revenue adversely (WHO, 2011).

9.4.8 Dying of heart failure

The process of dying was either through a gradual decline (which the family carers did not perceive death as imminent because they were not warned that the illness might result in death) or a sudden unexpected death following an acute event such as arrhythmias. Most (7) of our patients appeared to have sudden deaths. These results contrast with the findings of Seamark et al. (2002) that showed that most HF patients did not die suddenly. The difference in findings may be attributed to the availability of treatments that offer mortality benefits in the UK setting where Seamark et al.'s study was done, which could have influenced dying. However, larger studies in Uganda may give a better understanding of how patients with HF in Uganda die. Most family carers had not been told the prognosis of the condition and because in the past patients had had periods of exacerbation followed by recovery they expected recovery, and therefore some could have felt that the death was sudden and unexpected. The findings of the two ways of dying, however, is consistent with Seamark et al.'s study (2002) and has important implications for care and practice because it is difficult to prognosticate this group of patients. This 'prognostic paralysis' that has been identified in HF in the UK may delay initiation of a palliative approach leading to poor quality of life and quality of dying. Lessons learned from the UK in identification of patients suitable for a palliative care approach, such as after 2 unplanned hospitalisations or breathlessness at rest could be used to trigger such an approach (Johnson et al., 2012).

The majority of deaths happened in the hospital and only three at home, which contrasts with Johnson et al.'s findings (2012) who found that the majority of patients died at home. Previous research in Uganda showed that patients with life-limiting illness prefer to be cared for at home (Kikule, 2003), but it is not clear if they want to die at home or in hospital and further research to illuminate this is needed. It was found that not having information on whether one was dying or not, the state of the body, how quick death happened, and family carers' preferences influenced the place of death. The finding of the state of the body resonates with that of Lawton (2001), who found that if patients had 'unbounded' bodies they preferred to be admitted to a hospice although in our study those who were leaking fluid and had changed body image preferred to stay at home where they felt more secure and less embarrassed. Having information on whether ones was dying fits into Glaser and Strauss' theory of 'dying as non-scheduled status passage' and 'awareness of dying' (Glaser and

Strauss, 1965. Glaser and Strauss, 1966). One factor that could have led to more deaths in our population happening in hospital, is the lack of home-based care services for those with HF in Uganda, which is consistent with findings of Johnson et al. (2012) that home deaths were more common where there was access to palliative care services. This has implications for clinical care as the place of death is often considered as a measure of the quality of end of life care (Wilson et al., 2002).

9.4.9 Health professional-patient relationships

Participants had both positive and negative experiences of their health professionals. Some felt well cared for, reporting professionals as going beyond the call of duty, and contending with austere circumstances such as a high patient load, with very few staff and lack of many resources. However some participants reported that insensitive and rude communication, poor caring attitudes, and in lower health centres a lack of skills and knowledge contributed to negative experiences. Participants tended to describe a paternalistic patient relationship where the health professionals rarely informed them of what was happening to them and did not involve them in making decisions about their illness and lives. Previous research in health care in Uganda found similar findings of unpleasant encounters with health professionals, especially in public hospitals, which resulted in patients avoiding public hospitals and going to private hospitals or for alternative care/ traditional healers (Kiguli et al., 2009). This has important implications in the training of health professionals because previously the dominant approach to decision making was paternalistic but this has been challenged by ethicists, patients and health professionals, and the patient-health professional partnership is now advocated (Charles, Whelan and Gafni, 1999). The findings also have implications for the governing bodies of health professionals in Uganda to ensure discipline and research into the area of patient-health professional relationships, patients' expectations and health professionals' behavior.

9.4.10 Health professionals' perceived needs for patients versus patients' self-reported needs

Health professionals' perceived needs sometimes were consistent with the ones reported by the patients, but at other times they differed as demonstrated in Table 11 below. The lack of congruence between patients' and health professionals' rating of patients' health status has been reported elsewhere (Suarez-Almazor et al., 2001).

This may be because some needs are obvious to others such as health professionals because of their severity and the level of distress patients may express and because they are visible, but some other needs are more hidden although they may be equally or even more distressing and they are best told by the one having the experience. Health professionals are also trained to look for particular needs in different disease conditions, particularly symptoms and signs of the disease and therefore may omit some others not prescribed in the biomedical paradigm. From my experience before training in palliative care I was unaware of how needs in some domains such as the spiritual were expressed by patients and how to assess for them and probably for these health professionals a lack of awareness resulted into a lack of identification of these needs as previous research has found (Ellis, Vinson and Ewigman, 1999. King et al., 2013).

On the other hand, health professionals also sometimes have a privileged position with the patients and the latter may feel free to tell them more private needs or needs they think are more medically related, which they will not tell a researcher. This was observed when health professionals sometimes reported patients' needs that patients did not report to the researcher which they drew from their conversations with the patients. This is in line with what Richards and Emslie observed (2000) that patients tended to disclose different information to the doctor. They tended to tell doctors more medical issues including sexual issues and less of the other dimensions and when they were interviewed by a non-medical person they gave them more general information (Richards and Emslie, 2000). This may be the reason why health professionals did not have much to say on spiritual and psychosocial issues because they are less discussed by patients with them as they may think health professioanals are only interested in the medical issues.

Health professionals' perceived needs for information for patients were lower than that of the patients, and this may indicate the paternalistic approach to decision-making being dominant in the Ugandan setting. Needs such as that for nutritional support were not mentioned by patients as a specific need if they had money for food, they only mentioned it if there was complete lack of food, but to the health professionals this was a significant need. This is because patients probably did not pay much attention to the quality of what they ate as long as there was food whereas for the health professionals the quality mattered, including the use of salt and water intake. This is consistent with the findings above that the participants had health

illiteracy. The lack of time to take a comprehensive history from patients may also be a factor in health professions not reporting non-physical needs.

Table 11: Patients'and Health professionals' perceptions of needs in different dimensions

Patients' reported needs	**Health professionals perceptions of patients' needs**
Physical needs and concerns • Need to control all symptoms cardiovascular and others • Need for cure • Need to gain normal function status	***Physical needs and concerns*** • Emphasis on need to control cardiovascular symptoms • Need for treatments patients perceive as essential for ill patients such as intravenous fluids
Information needs and concerns • Mentioned spontaneously by all patients as an important need • Need for information on symptoms, the problem in the heart, disease cause, meaning of symptoms, prognosis, results of tests, disease progress, medications and their roles, self-care and presence of co-morbidities • Stressed need to get information in sensitive manner	***Information needs and concerns*** • Mentioned only when health professionals were prompted • Health professionals recognised need for information in only 3 areas : the diagnosis , adherence to treatment and prognosis • Expressed difficulty in communicating distressing news and heavy patient loads as barriers to information giving
Psychological needs and concerns • Need for reassurance, for counselling about treatment, to attain life goals, to attain a sense of completion and to maintain hope	**Psychological needs and concerns** • Need for counselling and emotional support, reassurance, addressing sexual needs and need for security
Social needs and concerns • Need for a predictable future, need for control, finances, practical help, to fulfill roles, for	**Social needs and concerns** • Need for financial support, nutrition support

independence, for companionship. Concern about family and life of loss.	• Need for acceptance in community
Spiritual needs and concerns • Spiritual concerns were present in all patients • Need for a sense of purpose, need to be valued, to be treated humanely, for spiritual support, spiritual satisfaction and healing	***Spiritual needs*** • Mentioned by only one health professional even on prompting • Need to pray

9.4.11 Health professionals' information on services available versus patients' information on the same

A comparison of health professionals' information on health services and information from patients on the same is presented in Table 12 below. Health professionals were aware of many available services especially for managing the disease of HF that patients were not aware of. Most of these services were being offered in the private services in Mulago Hospital. This may mean that patients in the general services, which are given free of charge, are not informed of these services probably because of the assumption that they may not afford them. Patients often thought these services had to be got from India because of the common appeals made over the radio for HF patients to be taken for treatment to India. Patients and health professionals were in accord in regards to deficiencies in services such as lack of medicines, understaffing in health services, lack of information services and inadequate information given and lack of hospital services for spiritual care. Most of these deficiencies in services are in line with findings of previous research done in Uganda on patients' perceptions of health care in general (Kiguli et al., 2009) and reflect challenges in the health system in Uganda.

In those areas where patients' and health professionals' perceptions were in agreement it was noted that health professionals' views tended to be more optimistic than those of patients, for example both recognised that there was lack of medicines, but health professionals felt the situation was much better than in the past, although patients could not see recent improvements. This is probably because health

professionals tended to see the larger picture while patients who lived through the experience could articulate that which was present and important to them. Morever, the patients may have been referring to the situation in their local health centers and the health professionals were referring to the situation in Mulago hospital. This has implications in which choice of perspectives should be taken for decision making for policy, as health professionals' views may underestimate the problem and patients may not see the bigger picture.

Services for social and psychological support were noted to be provided by some nurses but were not noted to be present by patients and this could be because their impact was not felt as the nurses are often too busy and may not make enough time for the patients, or because they were given implicitly, and patients could not separate them from the usual care given. Referrals to the social worker were few and reasons for this were not apparent, but it may be attributable to inadequate recognition of the multidisciplinary role by other health professionals in HF or because the department is overstretched and under-resourced and, therefore, its work is not felt on the ground. Further research to illuminate this area is needed. Both groups articulated barriers to quality care that included problems in the health system such as a lack of medicines and equipment for diagnosis, understaffing, congested services leading to lack of privacy, lack of family and community support, late presentation, and a lack of information among the patients. The finding of uninformed patients as a barrier to quality care is not unique to low-income settings but has also been found in research from high income countries (Browne et al., 2014), but not the other barriers and I would argue that these other barriers are more common in low-income countries where there is poverty, health illiteracy and challenges in the health system (Goudge et al., 2009).

Table 12: Health professionals' information on services available versus patients' information on the same

Patients' views	Health professionals' views
Services available for physical needs and those lacking • Hospital and outpatient clinics • Lack of most medicines • Lack of diagnostic facilities at lower centers • Congested services • Under staffed services • Advanced services can only be got from India	**Services available for physical needs** • In -patient, outpatient services • Services for the critically ill • Few community services • All diagnostics available in Mulago hospital • Advanced HF management including pacemakers and intra-cardiac devices, cardiac resynchronization • Lack of basic equipment for HF e.g., blood pressure monitors, weight scales • Some surgical interventions • More availability of medicines than before but still unsatisfactory • Poor levels of staffing
Services available to meet information needs • Information given to some randomly by health professionals on diagnosis and occasionally on self- care • No organized sessions for information giving • No information given in written form or visual /audio	**Services available to meet information needs** • Health professionals gave information on diagnosis and adherence to treatment, sometimes drug side-effects • Information not given on prognosis • Lack of information materials • Conceded that information given was limited
Services available to meet psychological needs • Health professionals have no time to be present to psychological needs • Mostly provided by their family carers	**Services available to meet psychological needs** • Nurses gave psychological support • Most felt this service was not yet developed for HF

Services available to meet social needs • Seemed to be unaware of social services in the hospital • Social care provided by the family and community	**Services available to meet social needs** • Nurse reported giving support • Hospital Social worker involved in some cases
Services available to meet spiritual needs • Did not mention any health related services • Spiritual care organized by patients or their families or religious communities	**Services available to meet spiritual needs** • No provision in health system for giving spiritual care • Spiritual leaders noted to come on the wards on their own volition to provide service
Barriers and challenges to quality care • Having to face the reality of dying every day when admitted on the wards, overcrowded wards leading to lack of privacy and fear of contracting new diseases, disruption of homes and businesses when one was hospitalized ,lack of order in the outpatient services, disruption of family carers' lives and lack of medicines and equipment for diagnosis and treatment.	**Barriers and challenges to quality care** • Inconsistent supply of medicines, understaffing, lack of family and community support, uninformed patients, presentation in advanced stages, inadequate self-care from patients, presence of precipitants of HF and failure of the system in recognizing the importance of a multidisciplinary team

9.4.12 Suggested ways of improving care by patients and health professionals

Patients and health professionals both suggested similar major themes of where improvement was needed, both in the health professionals and the health systems. However, there were differences in what both wanted to improve in both of these major themes. Under the theme of the health professionals, the interviewed health professionals centred on improving the knowledge and skills for diagnosis and

treatment of HF for health professionals at lower health centres, whilst the patients were more interested in improving the health professional-patient relationship through communication and professionalism. These suggestions fit in very well with the recommendations made for improvement of management of chronic disease in low and middle-income countries (Beaglehole et al., 2008).

There were many areas of concordance between patients' and health professionals' views on what should be improved in the health care system. These included: availability of medicines and diagnostic equipment; better coordination of care; improving social services and services for psychological support; and, providing information. Similar suggestions have been made from research in other settings especially in low and middle-income countries (Mills, 2014). Research in high-income countries emphasised the need for providing information (Harding et al., 2008). Health professionals also talked of additional measures that would be valuable including: a better referral system; health education of the public; education of the health professionals in multidimensional aspects of care; use of multidisciplinary teams; screening services for early detection of heart disease; palliative care; advanced surgical care for HF and home-based care.

Patients were not familiar with the concept of community-based care and when asked if it would be a way to improve care they either reluctantly agreed or felt it was too much to demand of health professionals. This may show attitudes of patients in this population who have very low expectations. Patients also expressed the importance of improving communication and relationships with their health care professionals, making investigations and tests financially accessible, improving emergency services, and reconsidering criteria for discharge of those who were hospitalised. These suggestions made by patients and health professionals fit in well with WHO six pillars of health system strengthening (WHO 2007) and recommendations for improving chronic disease care in low and middle-income countries (Beaglehole et al., 2008. Samb et al., 2010,), and it is interesting that even without health literacy, patients were able to articulate most of these.

Table 13: Patients' versus health professionals' suggestions on how care care can be improved

Patients' suggestions	Health professionals' suggestions
Patients suggestions were for the health system and the health professionals **Health professionals** • Improve communication: should have empathy, listen and pay attention to their needs and keep hope alive • Relating in a professional way: treat patients with respect give feedback on tests and treatments and involve patients and family in decision making **Health systems** • Improve availability of medicines • Making tests and investigations more financially accessible or free of charge • Better coordination of care • Improving emergency services for HF • Reconsider current criteria for discharge of those who have been admitted with HF • Counselling services • Providing information	Suggestions for health system and health professionals . **Health professionals**: • Building capacity for staff in lower health centres so as to be able to identify manage HF early • Increasing staffing numbers **Health systems** • Improve lower health care centers in diagnosis and treatment of HF • Strengthening the referral system and decongest Mulago Hospital • Consistent supply of medicines • Provide information services, services for psychological support and include palliative care services as part of comprehensive care for HF • Introduce screening services for early identification of heart disease and early treatment • Improve follow up services and consider community and home based care services • Better organized services and introducing specialized clinics for different causes of HF • Investing in advanced treatments for HF. • Health education of the public for prevention of heart disease, early referral and seeking care and to

	minimise stigma and promote empathy.

9.4.12 Living in the unknown

The overarching theme in the illness experience was that of living in the unknown and the experience of having HF appeared as journey, a movement from one unknown point to another, into an unknown land without any guide. As patients travelled this journey they found themselves moving further and further away from their homesteads, where they had hoped to be. Their description of life was like that of a person learning to live in a new uncharted land where there was a strange vocabulary and scarcity of interpreters to explain this language and to provide information on the unfolding events. Participants sometimes described going back and forth along already travelled paths or finding new routes that promised to lead them to cures. These hopes dominated participants' experiences until they became too disabled to continue to hope. Every patient's journey appeared to have distinct stages or landmarks that stood out in their narratives. These included the beginnings of their illness that led to a diagnosis, the treatment stages and the journey to death.

To my knowledge living in the unknown has not been described in the literature of patients with HF. This could be attributed to the fact that this literature originated from high-income countries that have higher health literacy rates especially on non-communicable chronic diseases such as HF and, therefore, there is knowledge about them in the public arena from Public Health awareness programmes. Public health campaigns for low-income countries such as Uganda however, have in the past been more focused on acute communicable diseases as they have been the leading causes of morbidity and mortality and therefore having a condition such as HF that is not reversible has been a less familiar situation in Uganda, and would explain the experience of living in the unknown.

The theme of living in the unknown, however, is a theme that has been described in a qualitative study with patients who have multiple sclerosis in high-income countries (Barker-Collo, Cartwright and Read, 2006). The authors explained that this was a dominant theme because of their participants' lack of information on multiple sclerosis, which is a rare condition and therefore there is less publicity on it and those who suffer from it have to discover event-by-event as they unfold. These findings

resonate with those in this study where it was found that there were high illiteracy rates and a high need for information.

Although living in the unknown was not found in the literature of patients with heart failure, the theme of uncertainty which is a very closely related theme was commonly mentioned in HF and other chronic illnesses. (Winters, 1997. Jurgens, 2006. Cleanthous et al., 2013) Mishel (1981) pioneered work on uncertainty in chronic illness and defined uncertainty as 'the inability to determine the meaning of illness related events.' (Mishel, 1981) She explains that 'it is a cognitive state created when the person cannot adequately structure or categorize illness related events due to a lack of sufficient cues.'(Mishel, 1988, p225) Therefore uncertainty occurs when illness situations are ambigious, complex, unpredictable and when there is insufficient information or inconsistent information. (Mishel, 1988) Mishel has elaborated two theories of uncertainty in illness that explicate how patients process illness-related stimuli and construct meaning in these events. (Mishel, 1988, p225) These include the Uncertainty in illness theory (UIT) which was first developed to address uncertainty during diagnosis and treatment of an acute illness and the reconceptualised uncertainty in illness theory (RUIT) that was developed to address the experience of ongoing uncertainty in chronic illness or illness with likelihood of recurrence. (Mishel and Clayton, 2008) The UIT theory has three themes; antecedents of uncertainty (anything that influences perception of illness-related events), appraisal of uncertainty (placing value of the illness event) and coping with uncertainty (includes danger, opportunity, coping and adaptation). The RUIT maintains the same definition and the three themes in the UIT but adds the concept of self-reorganisation and probabilistic thinking so as to address the process that occurs when one lives with unremitting uncertainty. (Mishel and Clayton, 2008 p56).

Uncertainty in patients with chronic heart disease and HF in literature from high income countries has been observed to be more prominent at the onset of symptoms, during diagnosis, when making treatment decisions, when adapting to therapies, during exacerbation of illness and when thinking of the future. (Winters, 1997. Jurgen, 2005.)

Uncertainty and living in the unknown are closely related because both may occur in ambiguous situations and where there is lack of or insufficient information. Additionally, living in the unknown may be an antecedent of uncertainty. However,

not all patients in this study who were living in the unknown had uncertainty, this is probably because they were able to give meaning to the illness events drawing on their belief systems and lay knowledge. For example symptoms and the illness were interpreted as due to God's will, witchcraft or as minor illnesses. Those who believed it was God's will did not have uncertainty because they had an attitude of surrender to a higher power and those who perceived the illness as minor, the lack of knowledge about the seriousness of their condition because they lived in the unknown helped them to prevent uncertainty. For some patients it was when inconsistent and alternative views about their illness were introduced by other lay people or health professionals that uncertainty developed. However, if patients got this new information and reconciled it with their beliefs or integrated it into their beliefs, they continued to have no uncertainty. Uncertainty also developed when expected outcomes such as resolution of symptoms were not achieved.

Uncertainty may exist even in those with good knowledge of the disease (those who are not living in the unknown) especially in situations where it is difficult to predict symptoms; infact uncertainty had been observed even among health professionals caring for patients. (Cleanthous et al., 2013) From the above discussion it appears that uncertainty involves a complex interplay of factors to occur, some of these factors are the same as those that determine living in the unknown however in uncertainty the inability to determine the meaning of illness related events is crucial.

CHAPTER TEN

10.1 Conclusions

This study provides key contributions to the understanding of patients living and dying with HF in a low-income country setting in Africa – Uganda. It provides new and detailed data on patients' perspectives of their changing illness and health service experience, their needs and concerns, and also the perspectives of health professionals who managed these patients.

This study demonstrated that both cardiovascular and non-cardiovascular symptoms are very common over the course of the patients' illness and that current assessment and treatment focusses largely on cardiovascular symptoms, and little attention is given to the frequent other non-cardiovascular symptoms. Patients' symptom burden resulted in acute episodes and then persistent loss of functional status resulting in significant treatment burden, repeated hospitalisations, dependence and loss of income. This study has described for the first time in Africa a typical trajectory of functional decline in patients with HF, which is similar to, but more rapidly progressive than the typical one described in studies done in high-income countries. (See figure 6 in discussion of results)

This study also brings an understanding of the delayed presentation and diagnosis of HF, which in Uganda is associated with health illiteracy, patient health-seeking behaviour and beliefs, and poverty among the patients. Lack of knowledge and skills amongst health professionals at lower health centres, coupled with a lack of diagnostic equipment exacerbated the delay in diagnosis.

Health system challenges including inconsistent drug supplies, congested clinics, uncoordinated services and poor communication and relationships with health professionals greatly impacted care by affecting patients' adherence /concordance to

treatment and follow-up care. The biomedical approach to illness, which stresses physical needs, that is currently used with these patients, was insufficient to meet the multidimensional needs and impact the illness had created on the patients including physical, information, social, psychological and spiritual needs. Most of these needs were not met by the health system either because they were not assessed or because services had not been developed to meet them. Many services available for managing HF were not geographically or financially accessible to the patients.

While most health professionals perceived the need for information for the patients to be limited to a few areas such as diagnosis, adherence with treatment and occasionally prognosis, patients wanted more information and it was apparent that they largely did not receive it. Lack of information led to anxiety, affected decision making and hindered self-care among the patients. With little information from health professionals, patients and their family carers made most health decisions based on lay knowledge and experiences and the patients' beliefs and culture. A significant social impact resulted from health illiteracy and a population that was already impoverished and had to meet treatment costs out of pocket, which led patients and their families to being trapped in a spiral of poverty and illness. While health professionals were able to articulate the social and psychological impact and needs of these patients, spiritual needs were not recognised by health professionals as being a concern despite being common and being a channel through which positive coping could be achieved.

Patients responded to the multidimensional illness impact by employing different coping and adaptation mechanisms and styles. Some of these were useful and can be encouraged and suggested by health professionals, but others were not useful and sometimes were harmful and should be discouraged. Patients' psychological, social and some spiritual needs reflected a desire for support with coping with the illness. Coping and adaptation enhanced adherence to treatment and better self-management in general.

More than a half of the patients in this study died, and almost half of all the deaths happened within two months of recruitment. Most deaths were unexpected by the

patients' families and more deaths happened in the hospital than at home. There was no medical, nursing or formal social support for patients who died at home.

Health professionals and patients suggested ways of improving care that were in congruence with the WHO six pillars of health system strengthening and also consistent with models of chronic disease care.

These findings indicate that an integrated approach to chronic disease care, which includes palliative care that involves holistic and multidisciplinary care, should be employed through the recommended WHO health systems strengthening in low-income countries for better patients' experiences. Furthermore the WHA resolution (WHO 2014) in 2014 called for all countries to integrate a palliative care approach for patients with all life-threatening illnesses in all settings, and this study provides much information on how this can be best done in Africa from patient, family and professional perspectives.

To my knowledge this is the first published qualitative longitudinal research in Uganda that has explored the experiences of patients with advanced HF to get an understanding of their needs and concerns from their perspective over the course of their illness from diagnosis to death and bereavement. Most research done in Africa on HF is quantitative and is centered on the epidemiology and treatment outcomes of HF. Thus, this thesis has also made contributions to this methodological approach of the use of serial qualitative multi-perspective interviews in a low-resource setting and a different culture.

10.2 Recommendations

Recommendations have been identified from this study for priorities in clinical care and service development; policy; health education for the public; training of health professionals and students; and research.

10.2.1 Priorities for clinical care and service development

The following were identified as priorities for improvement of services:

1. Routinely identify patients with HF of whatever cause who are at risk of deterioration for a palliative care approach. This consists of a holistic assessment, the starting of care planning, and offering co-ordinated multi-disciplinary support.
2. Improving the provision of information to patients with HF about diagnosis, possible course of the illness, and the importance of adherence to treatment.
3. Adapt successes in chronic care of HIV/AIDS such as: task shifting; home-based care; coordination of care; support of lower health centres; and, better referral systems, so as to enhance follow-up and decongest clinics in referral hospitals which will lead to more time for patients and hopefully better care.
4. Improve the availability of HF medications at all levels of the health system, so that initial and repeat prescriptions will be more available.
5. Improve on the functioning and availability of emergency services for patients with HF in hospitals as patients noted that when they were very ill and came to the hospital there was no proper system of triage which led to delayed intervention and sometimes patients died before interventions were given.

10.2.2 Priorities for health policy

1. There should be policies to address the 'brain drain' problem (where health professionals move to high-income countries for better living and working conditions) so as to improve health professional-patient ratios which will result in more time with patients, less strain on health professionals and better patient-health professional relationships and better care.
2. More effort should be put into adapting the approach recommended by the WHO on health systems strengthening whose pillars include: health financing; governance; health workforce; health information; medical products and technologies; and health service delivery. These pillars address most of the health challenges patients faced in this study and have the potential to reduce the poverty-illness cycle.
3. There should be government policies that protect workers who are ill or who develop disability because of illness. Some patients were sent away from their jobs without any support because they were not functional and were not getting any health insurance from their jobs.

4. There is need for the government to avail social services for those with chronic illness. Unmet social needs were very prominent in this study, and it was apparent that available functional social services were only provided by non-government organisations.
5. Health professional governing bodies, such as the Uganda Medical Association, should ensure continuous medical education for all health professionals, particularly those in lower health centres to update their information on best evidence and practices.
6. There is need for strengthening primary care, district hospitals and referral systems to provide care for patients with HF.

10.2.3 Priorities for health education for the general population

Health education was identified as an important priority in response to the identified low level of health literacy and to challenge and counter the high influence of lay beliefs and culture. There should be opportunities to engage with the general public and give them information, especially over the radio that is one the common sources of accessible information for the lay public. This information should be accessible to the general public by putting into consideration the low literacy levels. Efforts should also be made to include some of the basic information in primary and secondary school curriculum given the advent of free universal primary and secondary education in Uganda, with the hope of a more aware future population. Information could also be disseminated through faith leaders when faith groups gather together given that many people will attend prayers. Areas to be addressed in health education include;

1. Public education on the symptoms of HF and how to recognise the disease, as it was noted that to patients one was ill if severely functionally impaired and therefore patients presented with advanced disease.
2. Education on where to seek care when ill. For most patients, the initial response to change in wellbeing was to take get lay advice, use herbs or go to witchdoctors, which delayed seeking care from health care services.
3. Education on community support and empathy for those with chronic illness. This is because some patients were stigmatised because the public did not understand their illness and yet they needed community support.

4. Services available for patients with HF and how to access them. Most patients were not aware of the services available that could have helped their well-being.

10.2.4 Priorities for education and training for qualified and not yet qualified health professionals (nurse, doctors, clinical officers)

1. Training in medical schools and for health professionals should be based on a more encompassing model than the current biomedical model, that is a model that embraces multidimensional and multi-disciplinary care and training, which addresses both the disease and the illness.
2. All health professionals should be trained in palliative care and how to identify patients who need a palliative care approach, so they can integrate it in the care they provide.
3. Training should emphasise and model ethical practices of shared decision making, good communication skills, and desired patient-health professional relationships. Good communication should be emphasised and assessed during training as most patients felt it was an area that was lacking in their care.

10.2.5 Priorities for future research

1. More research is needed to determine when a palliative care approach in HF patients in Uganda should be initiated given the available resources, the best models of care and on where patients with this condition want to die.
2. Further research is needed to establish effective methods of giving information to patients about their illness in a population with high illiteracy rates. An information pamphlet could be designed from information obtained from this research and then given to patients in print and also by other means, such as videos played during the clinic times or given by nurses in organised sessions in the clinic, and compare which means is most effective.
3. A follow-up quantitative study using information generated from these findings would be useful to determine the views of a larger number of people with HF in Uganda and to determine if changes in needs over time are statistically significant and to determine factors associated with the different needs.

4. Given the high attrition rates longitudinal research might have, frequent serial interviews to get a clearer picture of the changes, which tend to happen dramatically over a short period may be more useful. The intervals could be determined by having a pilot cohort study before the longitudinal research begins to get a rough estimate of survival, and should extend for a period of time by which around 50% of participants may have died so that the last days of life are also captured.
5. Independent family carer interviews would be useful in illuminating not only their own needs as carers but also the illness experience as regards to how the patients related with their family carers and the community, and those areas of the patients' experience patients may not have noted themselves such as psychological needs.
6. Focus group discussions with health professionals on their perception of patients' needs and how to improve services may give more insights especially in the area of care improvement, because there would be a chance to discuss and debate the different ideas arising with people of different levels of expertise and exposure leading to more concrete suggestions. Also, one person's ideas may spark off ideas from others leading to a variety of suggestions. Reasons for less referral to services such as social work would also be explored.
7. Other methods of doing interviews such as the use of telephone interviews could be employed in addition to face-to-face interviews for those from hard to reach geographical areas. This would provide an all-encompassing view of the illness experience for patients from rural and urban areas in low-resource settings, where access to these areas may not be feasible for the researcher.

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APPENDICES

Appendix One: Information sheet for study participants

Title: Improving care for people on heart diseases wards in Mulago hospital, Uganda.

My name is Elizabeth Namukwaya and I am inviting you to take part in a research study. Before you decide if you want to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and if you want you can discuss with others before deciding whether or not you wish to take part. Please get in touch if there is anything that is not clear or if you would like more information.

What is the purpose of the study?
I want to find out from people who have been admitted to the heart diseases ward what it is like living with their illness. I am interested to hear all about their life and what they have gone through since their condition started, any issues they have had and any suggestions of how their lives with this condition could be improved. I want to hear about all aspects of their lives in the hospital and at home.

Why have I been chosen?
You have been chosen because you have been admitted to the ward for people with heart conditions at Mulago Hospital. The doctors and nurses here think you might be suitable to take part in the study. I hope to speak to another 15 patients in a similar situation to you. I would also like to talk to doctors , nurses and people working in the health service who are involved in the care of people with a similar condition as yours or who might be involved in your care in the future to get their views on how care for you and people with conditions such as yours can be improved.

Do I have to take part?
You are completely free to decide whether or not you would like to take part. Your medical care will not be affected in any way if you decide to participate in this study or not.This study is completely separate from your medical treatment.
If you are at all interested in taking part then you will be given this information sheet to keep and given the chance to think about it. I will be in touch with you to answer any other questions and see whether or not you would like to take part. You are free to withdraw from the study at any time without giving any reason. Again, this will not affect the standard of your care in any way.
What will happen to me if I take part?
I will arrange a time to come and talk to you either at home or at a place you choose and on a date that is convenient to you. I will come to speak to you for between 15 minutes to over an hour depending on how much you have to say. If you prefer your

main carer to be present during your interview together with you we shall arrange for that to happen.

I will ask you some questions about what your life has been like since this illness started. Your life in the hospital, at home and in the community. I will ask you about things or people you have found helpful during the time of the illness, things that have not been helpful and your ideas about how things could be made better for you, your family and other people with similar conditions to yours. If you agree the interview will be recorded so that I can listen back and make sure I interpret what you say correctly. The information you give me will be stored securely and only listened to by the research team. Your interview will be typed out to help me read it out and understand better. If you agree I would also like to read your ward notes to give me a better understanding of your illness.

I would also like to come and speak to you again in future if you agree because I also want to understand what it is like living with your illness over time not just the time I first see you . If you still want to participate in this research in the future but you do not feel well enough to talk, with your permission I shall interview your carer to help me understand how you are at that time.

If you agree I shall take your phone contact and or that of your family carer and I shall give you a call to ask you if you want to continue to participate in the study.

What are the potential benefits?
There may not be direct medical benefits to you from taking part in this study. The study aims to improve care for patients like you in the future. Hearing your and other people's views with this condition will help me in understanding how life for those who are ill can be improved. Patients who have taken part in similar previous studies have generally found it helpful and we hope you will have the same experience.

Will my taking part in the study be kept confidential?
Yes. Your name and contact details will not be known to anyone other than myself and no information will be given to anyone outside of the research team. Your doctors do not need to know that you are taking part in the study if you would prefer it that way. However, I will speak to doctors and nurses who take care of patients with your condition in this hospital to get their views about how care can be improved. Any thing you say in the interview will be private and confidential and no one outside of the research team will know what you have said. Any names, places or other features which may identify you will be removed from the typed out information so that you cannot be identified. Any quotes from what you have said to us that are used will therefore be anonymous. The recorded interviews will be stored securely and will not bear your name and they will be erased in due course.

What will happen to the results of the study?

We will write reports in medical and other professional journals so that doctors, nurses and other health professionals can understand what people's lives with your condition is like and what matters to you and how provide better care can be provided.

What if something goes wrong?
We do not anticipate any harm occurring to you from taking part in this research. But, if something goes wrong there are no special compensation arrangements. However, if you have any complaints about the research forward them to the chairman of the Mulago hospital ethics committee Dr. Fred Nakwagala telephone number 256772325869.

Who is organizing the study?
The study is being organised by myself as part of my doctoral studies and I am working with a team of researchers at the University of Edinburgh and School of Medicine Makerere University who are supervising my doctoral studies.

Contact for further information:
If you have any questions or you would like to discuss any aspects of the study before deciding to take part, you can contact Elizabeth Namukwaya mobile phone number 0772595672.

Thank you for taking your time to read this information sheet and considering this study.

Please feel free to get in touch if you have any questions.

CONSENT FORM FOR PATIENTS

Improving care for people on the heart diseases wards in Mulago hospital, Uganda.

Researcher: Elizabeth Namukwaya

		Please initial
1.	I confirm that I have read and understand the information sheet for the above study and have been able to ask questions	
2.	I understand that my participation is voluntary and I am free to stop or with draw at any time, without giving any reason, and without my medical or legal rights being affected.	
3.	I agree to my interview being tape- recorded and written down and understand that any written version will be anonymous (my /our names will not appear on the written versions).I will have the opportunity to review the transcript if I request.	
4.	I agree to a written version of my/our interview being stored carefully without my name on it.	
5.	I agree to the researcher reviewing my ward notes	
6.	I want my carer to participate in the interview	
7.	I want my carer to give information about my disease in future interviews if Iam not well enough to talk	
8.	I agree to the researcher calling me after discharge	
9.	I wish to receive a copy of the results of this study	
10	I agree that anonymised information from the interviews may be used in medical journals.	
11	I agree to take part in the above study	

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Name of participant Date Signature

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Name of researcher Date Signature

CONSENT FORM FOR THE FAMILY CARER THAT WERE PART OF THE PATIENT INTERVIEW

Improving care for people on the heart diseases wards in Mulago hospital, Uganda.

Researcher: Elizabeth Namukwaya

		Please initial
1.	I confirm that I have read and understand the information sheet for the above study and have been able to ask questions	
2.	I understand that my participation and giving information about my patient is voluntary and I am free to stop or with draw at any time, without giving any reason, and without my patient's medical or legal rights being affected.	
3.	I agree to my interview being tape- recorded and written down and understand that any written version will be anonymous (my /our names will not appear on the written versions).I will have the opportunity to review the transcript if I request.	
4.	I agree to a written version of my/our interview being stored carefully without my name on it.	
5.	I wish to receive a copy of the results of this study	
6.	I agree that anonymised information from the interviews may be used in medical journals.	
7.	I agree to take part in the above study	

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Name of participant Date Signature

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Name of researcher Date Signature

Appendix Two: Sympathy note to bereaved carer

Dear ----------

Please accept my heart felt sympathies for your loss of ---------- (deceased's name) . I know how difficult this must be for you. You are in my thoughts and prayers.

---------- (deceased name) was a gentle (or any other good qualities the researcher would have noticed in the course of the interviews) . I know how much you will miss him/her. I was deeply moved by the devotion you and your family showed in ----------care. If you would like I can come over any time and we talk over your feelings and concerns. I shall call you to find out if you would like to talk.

May God bless you and console you and your family during this time and always. I hope your fond memories of ----------will give you great comfort.

Sincerely

Elizabeth

INFORMATION SHEET FOR BEREAVED CARERS

Improving care for people on heart diseases wards in Mulago hospital, Uganda.

My name is Elizabeth Namukwaya and I am inviting you to take part in a research study. Before you decide if you want to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and if you want you can discuss with others before deciding whether or not you wish to take part. Please get in touch if there is anything that is not clear or if you would like more information.

a) What is the purpose of the study?

I want to find out from people who have been referred to the heart diseases ward what it is like living with their illness. I am interested to hear all about their life and what they have gone through since their condition started, any issues they have had and any suggestions of how their lives with this condition could be improved. I want to hear about all aspects of their lives with this condition in the hospital and at home.

b) Why have I been chosen?

You have been chosen because your loved one was involved in this study before his/her death and gave me important information about his condition. I also want to find out what their life was like during their last days, what their concerns were and how care could have been made better. This is so we can improve the care for patients with similar conditions in the future.

c) Do I have to take part?

You are completely free to decide whether or not you would like to take part.
If you are at all interested in taking part then you will be given this information sheet to keep and given the chance to think about it. I will be in touch with you to answer any other questions and see whether or not you would like to take part.

d) What will happen to me if I take part?

I will arrange a time to come and talk to you on a date that is convenient to you. I will come to speak to you for between 15 minutes to over an hour depending on how much you have to say.

I will ask you some questions about your loved ones's life during their last days, what their needs and concerns were and how care could have been improved for them. I understand this may be difficult for you and we can stop the interview at any time you want. If this interview causes a lot of distress to you, I can seek psychological help for you.

If you agree I shall give you a call and we arrange when I can talk to you.

e) What are the potential benefits?
There may not be direct benefits to you from taking part in this study. The study aims to improve care for patients like your loved one in the future. We also hope that you find it helpful to have an opportunity to talk about what mattered to your loved one.

f) Will my taking part in the study be kept confidential?
Yes. Your name and contact details will not be known to anyone other than myself and no information will be given to anyone outside of the research team Any thing you say in the interview will be private and confidential and no one outside of the research team will know what you have said. Any names, places or other features which may identify you will be removed from the typed out information so that you cannot be identified. Any quotes from what you have said to us that are used will therefore be anonymous. The recorded interviews will be stored securely and will not bear your name and they will be erased in due course.

g) What will happen to the results of the study?
We will write reports in medical and other professional journals so that doctors, nurses and other health professionals can understand what people's lives with conditions such as the one your loved one had is like, what matters to them and how better care can be provided.

h) What if something goes wrong?
We do not anticipate any harm occurring to you from taking part in this research. Some people think that talking about these situations may upset them. I reassure you that you can stop the interview whenever you feel you cannot continue. Also if there is further distress I shall refer you to get support from a bereavement service. There are however no special compensation arrangements. However, if you have any complaints about the research forward them to the chairman of the Mulago hospital ethics committee Dr. Fred Nakwagala telephone number 0782119498.

i) Who is organizing the study?
The study is being organised by myself working with a team of researchers at the University of Edinburgh and School of Medicine Makerere University who are supervising my doctoral studies.

Contact for further information:
If you have any questions or you would like to discuss any aspects of the study before deciding to take part, you can contact Elizabeth Namukwaya mobile phone number 0772595672.

Thank you for taking your time to read this information sheet and considering this study.
Please feel free to get in touch if you have any questions.

CONSENT FORM FOR BEREAVED FAMILY CARER

Improving care for people on the heart diseases wards in Mulago hospital, Uganda.

Researcher: Elizabeth Namukwaya

		Please initial
1.	I confirm that I have read and understand the information sheet for the above study and have been able to ask questions	
2.	I understand that my participation and giving information about my patient is voluntary and I am free to stop or with draw at any time, without giving any reason, and without my legal rights being affected.	
3.	I agree to my interview being tape- recorded and written down and understand that any written version will be anonymous (my /our names will not appear on the written versions).I will have the opportunity to review the transcript if I request.	
4.	I agree to a written version of my/our interview being stored carefully without my name on it.	
5.	I wish to receive a copy of the results of this study	
6.	I agree to take part in the above study	
7.	I agree that anonymised information from the interview may be used to write articles for medical journals	

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Name of participant Date Signature

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Name of researcher Date Signature

Appendix Three: Information sheet for health professionals

Improving care for people on the cardiac wards in Mulago hospital, Uganda.

My name is Elizabeth Namukwaya Iam a medical doctor in the palliative care unit and I am inviting you to take part in a research study which I am doing as part of my doctoral studies. Before you decide if you want to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss with others before deciding whether or not you wish to take part. Please get in touch if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The study aims to improve the holistic care of people diagnosed with advanced (NYHA stage 4) heart failure. I will explore the views of patients and the health professionals involved in their care in order to understand their experience and identify any unmet needs. As part of the project, I am going to interview a number of health professionals and social workers involved in the care of these patients.

Why have I been identified?

I am interested in speaking to you because you have been identified as a professional working in the treatment, care or support of a person diagnosed with advanced heart failure in Mulago hospital.

What does the study involve for me ?

If you consent to taking part, I will arrange a time to visit you at work or another place at a time that is convenient and interview you.. Telephone interviews can be arranged if this is preferable. The interviews are expected to last 15-40 minutes and will cover a range of topics about your experience of being involved in the care/management of a patient with advanced heart failure. I am interested to hear about your views on how patients' care can be improved to make their lives better and on aspects of the service that could be improved in order to make it easier for you to offer them the best care possible. Iam interested in hearing about how you have been involved in your patients' care and how this was facilitated or inhibited. Your interview will be recorded and transcribed for analysis. All interview data will be confidential and anonymous with personal and health professional identifiable features removed.

What are the potential benefits?

There may not be direct benefits to you participating in this research. This research will however benefit all health professionals taking care of health failure patients in understanding their patients' multidimensional needs and how to improve their care.

Will my taking part in the study be kept confidential?
Your name and contact details will not be known to anyone other than myself and no information will be given to anyone outside of the research team. Any thing you say in the interview will be private and confidential and no one outside of the research team will know what you have said. Any names, places or other identifiable features will be removed so that you cannot be identified. Any quotes from what you have said to us that are used will therefore be anonymous. Recorded interviews will be stored securely and erased in due course.

Who is organizing the study?
The study is being organised by myself as part of my doctoral studies and Iam supervised by a team of researchers at the University of Edinburgh and School of Medicine Makerere University.

What will happen to the findings of the study?
The findings of the study will be written up in the form of a report and articles published in peer reviewed journals. The recommendations made will inform health and social care provision. The findings will also inform the development of interventions to improve care for patients with advanced heart failure and their families.

Contact for further information:
If you have any questions or you would like to discuss any aspects of the study before deciding to take part, you can contact Elizabeth Namukwaya mobile phone number 0772595672.

Thank you for taking your time to read this information sheet and considering this study.
Please feel free to get in touch if you have any questions.

Consent form for Health Professionals

Improving care for heart failure patients in Uganda.
Researcher: Elizabeth Namukwaya

		Please initial
1.	I confirm that I have read and understand the information sheet for the above study and have been able to ask questions	
2.	I understand that my participation is voluntary and I am free to stop or with draw at any time, without giving any reason, and without my medical or legal rights being affected.	
3.	I agree to my interview being tape- recorded and written down and understand that any written version will be anonymous. I will have the opportunity to review the transcript if I request.	
4.	I agree to a written version of my/our interview being stored carefully without my name on it.	
5.	I wish to receive a copy of the results of this study	
6.	I agree that anonymised information from the interviews may be used in medical publications	
7.	I agree to take part in the above study .	

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Name of participant	Date	Signature
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Name of researcher	Date	Signature

Appendix Four: Information and consent form for patients translated into Luganda

Okusaba olukusa okwetaba mukunontereza kunno n'e bikwata ku kunonyereza kuno

Omutwe: Ebyetagiisa mu kulongosamu mu bujjanjabi bwa abalwadde bo mutima mu dwaliro ly'e Mulago.

Elinya lyange nze Elizabeth Namukwaya ndi muyizzi nga nsoma PhD okunnyamba okuguka mu kunonyereza ku mbera ez'obulamu n'endwadde z'abantu. Nkusaba wetabbe mukunonyereza kuno, naye, nga tonasalawo nkusaba otwale obudde osome ekiwandiko kino wetegereze okunonyereza kunno bwe kunakolebwa ne biki ebinakwetagisibwa bwonoba osazewo okukwetaaba mu. Bwoba ngolina ekibuuzo kyona oba nga waliwo ekitategelekese totya kumbuzza ekisera kyonna kyondaba oba nkubira essimu gyengenda okuwa wanno wamanga.

a) Ekigendererwa n'okunnyonnyola kukunonyereza
Okunonyereza kugenderera kwebuzza kwabo abali ku waddi yabalina endwadde z'omutima bye'bayitamu okuva bwebafunna obulwadde bunno. Ekigendererwa kwe okumanya buli kimu mu bulamubwo (obwo' mumubiri, mwoyo, endowooza, ne mukolaganazo na bantu) ng'olimulwadde. Obulamu bwo mudwaaliro n'ekka, n'emubulamubwo bwonna. Twagala n'okufuna endowooza yo ku bikki ebiyinza okukolebwa okulongoosa obujjanjabi n' ebeera yobulamu obwabo abalina enddwade z'omutima.

b) Lwakki nondedwa okwetaba mukunonyereza kunno?
Olendedwa kubanga bakuwadde ekitanda ku waddi yabalwadde b'omutima. Abasawo ba waddi eno balowooza nti oli omu kwabbo abasana okwetaba mukunonyereza kuno. Mukunonyereza kono, nsubira okwogera n'abantu abalala kuminabatano abalikuwaddi eno era ngabalina obulwadde nga obubwo. Njakwogerako n'abasawo abajjajamba obulwadde bunno okufuna endowozza zabwee ku ebyo ebyetagisibwa okulongoosa kubujanjabi bwabo abalina obulwadde ng'obubwo.

c) Kya teeka okwetaba mu kunonyereza kunno?
Needa, kirigyoli okusalawo oba oyagala okwetaba mukononyereza kuno. Ne bwonogaana okwetaba mukononyereza kuno obujjanjabi bwo tebujja kukosebwa. Okunonyereza kunno tekukwatagana na bujjanjabi bwo bwofuna kati.
Bwoba waliyagadde okwetaaba mukononyereza kunno ojakuwebwa ekiwandiko kino n'o budde okisime weka ate okilowoozeko. Njakudda okukuddamu ebibuuzo byonna byewaliyagadde okubuuza n'okukakasa oba oyagala okwetaba mu kunonyereza kunno. Oliwadembe okusalawo okulekerawo okwongera okwetaba mu kunonywereza

kuno ekisera kyonna ne bwotawa nsonga yonna era kino tekija kukosa bujjanjabi bwo.

d) Kiki ekinabaawo bwenetaaba mu kunonyereza kunno?
Tujja kukiriziganya olunaku n'obudde nkomewo twogele okumala ekiseera ekyedakiika okuva ku kuminataano okutuuka mu sawa emu okusinzira ku gwe byonoyagala okwogerako. Bwoba oyagala omujjanjabi wo aberewo nga twogera tujja kumusaba okubeera wo. Mu kunonyereza nja kukubuuza ebibuzo ku bulamu bwo bwe bubadde okuva bwe watandika okulwala, mudwaliro ne eka ate nemu bulamu kukyalo. Nja kukubuza abantu abakuyambye mu bulwadde bbunno n'e ebintu ebikyambye mu bulwadde bye waliyagaliza abo abalina obulwadde nga bunno bamanye kibayamabe okukyusa kumbeera yabwe. Njakukubuza n'ebyo byonna gwe na abewaakawo ebibayambye mu kiseera kyonna ekyobulwadde.

Byonoba okirizza njagala kukwata bye tunanyumya kulutambi kinyambe okujukiira byoyogedde neme kukyusa bigambo. Nkukakasa nti byonongamba ebinaba kulutambi tewali muntu ajja biwulira okujako abo bokka abali mukunonyereza kuno. Era bino ebili kulutambi tujja biwandika kumpapula okutuyaamba oku bitegera nga tubisoma naye tebijja kuberako linnya lyo era tetujakulaga ku ani gye tujje ebbigambo binno. Mbande nsaba ntunuleko ne mu biwandiko byo ebya wadi okumanya ekisingawo ku bulwadde bwo nga abasawo bwe banaba bawandise.

Naliyagadde okukomawo mukiseera ekyomumaso nga tumazze okwogera omulundi ogusooka tudemu twogere kumbera yo nga bweneba ekyusse bwonoba onzikiriza okujja wonna wonoba. Bwonoba tewewula bulungi naye ngawaliyaggadee okwongera okwetaba mukunonyereza kunno bwonoba okiriza njakwogera n'omujjanjabi wo okumannnya nga bwoli.

Bwonoba okirizza nsaba ompe kunamba ye simu yo ney'omujjanjabi kwe nabakubira okumanya oba oyagala nzijje twogele.

e) Kikikyenafuna mu?
Okunonyereza kunno kujja kutuyamba okukyusa obujjajambi obuwebwa abalwadde nga gwe okuyamba embeera y'o bulamu bwabwe ebeere nungi naye kisoboka nti oyinza obutafunamu nnyo mangu ddala ng'omulwadde. Abalwadde abeetaba mukunonyerezza okufanana kuno bagamba kibayamba era tusubira ntinawe onobeera nga bbo.

f) Okwetaba mu kwange kunabeera kwa nkisso?
Yee. Erinyaa lyo ne namba yasimu siyina muntu yenna gwengenda kubiwaa. Bwetunaba twogela kulutambi erinnya lyo sijja kulyogera naye njakuliwandika kulupapula lwawuffu awamu ne gyobera okukakas nti tewali asobola kumanya ki kyoyegedde. Bye tunakwata kulutambi njakubisangula nga okunonyereza kunno kuwedde.

g) Ebinava mukunonyereza munabikola mutya?
Tujakuwandika alipooti mu butabo bwabaasawo basobole okumannya obujjanjabi bwamwe bwe buyinza okulongosebwamu ne bye mwaliyagadde biberewo oba bikyuke naye amannya gamwe tetuja kugawandikamu.

e) Munakolaki bwe wanabbera wo omutawana
Tetusubira ntiwanabeera wo omutawana gwonna nga wetabye mukonyerzza kunno kubanga tugenda kwogera bwogezzi era tetutadeewo ntekanteka yonna eyokusasula muntu yenna. Naye bwo noba olina okwemulugunya kwonna mukunonyereza nga kutandise okubira esimu sentebe wa kakiko akalaba nti okunonyereza okwabulingeri mu dwalilo lye Mulago kugenda bulungi ye Dr. Nakwagala ku siimu 0782119498

h) Ani atekateka okunonyerezza kunno?
Nze tekakateka okunyerezza kunno ngabwe nagambye nti ndi kumisomo gyage egya PhD nga nyambibwaako abasomesa bange abava mu tendekero lya univasite eya Edinburgh ebulaya.

Okumannya ebisingawo
Bwoba oyagala okumnnya ebisingawo kukunonyerza kunno nga tonasalawo kuba esimu yange Elizabeth Namukwaya number 0772595672.

Webale nnyo okutwala obudde bunno okusoma binno, nkubira esimu bwoba olina ekibuzo kyonna

Okusaba Olukusa olwokwetaba mukunonyereza kunno. (yamulwadde)

Omutwe: Ebyetagiisa mu kulongosamu mu bujjanjabi bwa abalwadde bo mutima mu dwaliro ly'e Mulago.
Omunonyereza : Elizabeth Namukwaya

		Tekawo akabonero akagolola bwobakirizza
1.	Nkakasa nti nsomye nentegeera ebikwata ku kunonyereza kunno n'embuzza nebibuuzo	
2.	Ntegedde nti okwetaba mukunonyerezza kunno kwa kyeyagalile, era nsobola okuva mu kunonyerezza kunno nga siwadde nsonga. Kinno tekijja kukosa bujajjambi bwange oba bwe nayisibwa	
3.	Nzikiiriza byetwogera okubiteeka kulutambi era ntegedde nti bwe banabiwandika kulupapula tekujakubelako kilaga nti nze nabyogela. Bwe nayagala nsobola okusaba byebawandise nebisoma okukukasa nti bituufu	
4.	Nzikiiriza okutereka ebyo ebinaba biwandikidwa kasita erinnya lyange oba ekilaga nti nze nabyogela baba babijeko	
5.	Nzikiiriza bakebere kubiwandiko byange ebya wadi	
6.	Njagala omujjajabi wange abelewo nga twogela	
7.	Njagala omujjanjabi wangi okunjogerera bwe naba sewulila bulungi ku milundi egidako	
8.	Nzikiriza okunkubira esimu nga bamazze okunsibula	
9.	Njagala bampe kulipota enava mukunonyereza kunno	
10.	Nzikiriza nti byenjogedde babiwandike nu butabo bwabasawo naye bajje ko erinnya lyange oba kyonna ekilaga nti nze eyayogela	
11.	Nzikiriza okwetaba mukunonyereza kunno	

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erinya lyo mwetabi omukono enaku z'omwezi

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erinya lyomunonyerezi omukono enaku z'omwezi

Okusaba Olukusa olwokwetaba mukunonyereza kunno. (yamujanjabi)

Omutwe: Ebyetagiisa mu kulongosamu mu bujjanjabi bwa abalwadde bo mutima mu dwaliro ly'e Mulago.
Omunonyerezi: Elizabeth Namukwaya

		Tekawo akabonero akagolola bwobakirizza
1.	Nkakasa nti nsomye nentegeera ebikwata ku kunnyereza kunno n'embuzza n'ebibuuzo	
.2.	Ntegedde nti okwetaba mukunonyerezza kunno no kwogera ku biffa kumulwadde wange kwa kyeyagalile, era nsobola okuvamu kunonyerzza kunno nga siwadde nsonga. Kinno tekijja kukosa bujajjambi bwamulwadde ne bwanayisibwa	
3.	Nzikiiriza byetwogera okubiteeka kulutambi era ntegedde nti bwe banabiwandika kulupapula tekujakubelako kilaga nti nze nabyogela. Bwe nayagala nsobola okusaba byebawandise ne mbisoma okukukasa nti bituufu	
4.	Nzikiriiza okutereka ebyo ebinaba biwandikidwa kasita erinnya lyange obe ekilaga nti nze nabyogela banaba babijeko	
5.	Njagala bampe kulipota enava mukunonyereza kunno	
6.	Nzikiiriza nti byenjogedde babiwandike nu butabo bwabasawo naye bajje ko erinnya lyange oba kyonna ekilaga nti nze eyayogela	
7.	Nzikiriza okwetaba mukunonyereza kunno	

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erinya lyo mwetabi omukono enaku z'omwezi

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erinya lya munonyerezi omukono enaku z'omwezi

Appendix Five: Sympathy note translated into Luganda

OBUBAKA OBWOKUSASIRA

Eri..omwami/omukyala .....
Nsaba okutuusa obusasizi nokukubagiza bwange ewuwo n'abomumaka go olwokufirwa omuntu wamwe.....

Obudde nga bunno buzibu nnyo eri abo abafiridwa era muli mu bilowoozo ne musala zange.

..... abadde muntu mulungi ate mugumikiriza era mannyi obutababawo bwe bulese ekiwuubaalo.

Mwebale nnyo okumulabilia nga mulwadde mwamulaga okwagala n'omukwano. Bwoba oyagala njakujja twogele ku ngabwowulila. Njakukubila esimu nkakase oba oyagala nzijje.

Katonda akukume ate akukubagize nabawakawo mukisela kinno.

Nze

Elizabeth

Consent form and information sheet for bereaved carers translated into luganda

Okusaba olukusa n'e bikwata ku kunonyereza kuno (bajjanjabi)

Omutwe: Ebyetagiisa mu kulongosamu mu bujjanjabi bwa abalwadde bo mutima mu dwaliro ly'e Mulago.

Elinya lyange nze Elizabeth Namukwaya ndi muyizzi nga nsoma PhD okunnyamba okukuguka mu kunonyereza ku mbera ez'obulamu n'endwadde z'abantu. Nkusaba wetabbe mukunonyereza kuno, naye, nga tonasalawo nkusaba otwale obudde osome ekiwandiko kinno osobole okwetegereza okunonyereza kunno bwe kunakolebwa ne biki ebyekwetagisibwa bwonoba osazewo okulwetaaba mu. Bwoba ngolina ekibuuzo kyona oba ngawaliwo ekitategelekese totya kumbuzza ekisela kyonna kyondaba oba kusimu gyenakuwa wamanga.

a) Ekigendererwa n'okunnyonnyola kukunonyereza kunno
Okunonyereza kugendelela kubuzza abo abaliku waddi yabalina endwadde z'omutima kye'bayitamu okuva bwebafunna obulwadde bunno. Tugendelela okumanya buli kimu mu bulamubwabwe (mumubiri, mwoyo, endowooza, ne mukolaganazo na bantu) ngabalwadde,obulamu bwabwe mudwaaliro n'ekka, nemubulamubwabwe bwonna. Twagala n'okufuna endowooza yabwe ku bikki ebiyinza okukolebwa okulongoosa obujjanjabi n' ebeera yobulamu obwabo abalina enddwade z'omutima.

b) Lwakki nondedwa okwetaba mukunonyereza kunno?
Olendedwa kubanga omulwadde woyetaba mukunonyerezza kunno nga akyalimulamu era nambulila ebyomugaso bingi kukujanajaba abalwadde ngaye. Njagala okweyongera okumanya obulamu bwe bwebwali munaku ezasembayo biki bye yali ayagal era kiki ekyalikoledwa okulongosa obujjajabi bwe. Okusobola okutuyamba okuyamba abalwadde abalala abo bulwadde bunno.

c) Kyateeka okwetaba mu kunonyereza kunno?
Needa, Kirigyoli okusalawo oba oyagala okwetaba mukononyereza kuno. Bwoba waliyagadde okwetaba mukononyereza kunno ojakuwebwa ekiwandiko kino n'o budde okisome ate okilowoozeko. Njakudda okuddamu ebibuuzo byonna byewaliyagadde okubuuza n'okukakasa oba oyagala okwetaba mu kunonyereza kunno. Oliwadembe okusalawo okulekerawo okwongera okwetaba mu kunonyerereza kuno ekisera kyonna ne bwotawa nsonga yonna.

d) Kiki ekinabaawo bwenetaaba mu kunonyereza kunno?
Tujja kukiriziganya olunaku n'obudde nkomewo twogele okumala ekiseera ekyedakiika okuva kuminataano okutuuka mu sawa emu okusinzira ku gwe byonoyagala okwogerako.

Nja kukubuuza ebibuzo ku bulamu bumulwadde wo nga bwebwali munaku ezasembayo, biki byeyali yetagga, oba byeyali ayagala era mundowozayo obujanjabi bwe bwalibadde bulogosebwa butya.

Nkimanyi nti okwogrea kumulwadde wo kiyinza okuleeta enaku era tujja okukoma wonna wonoyagala okoma okwogela. Okwogera kwaffe bwe kunaleeta eyiinike enyigi bwonoba oyagala njakutwala oyogele nabakuggu mu bye bilowozo, nokukubagiza.

Byonoba okirizza njagala kukwata bye tunanyumya kulutambi kinyambe okujukiira byoyogedde neme kukyusa bigambo. Nkukakasa nti byo onongamba ebinaba kulutambi tewali muntu ajja biwulira okujako abo bokka abali mukunonyereza kuno. Era bino ebilikulutambi tujja biwandika kulupapula okutuyaamba okubitegera nga tubisoma, naye tebijja kuberako linnya lyo era tetujakulaga waa gye tujje bigambo binno.

Bwonoba okirizza nsaba ompe kunamba ye simu yo kwe nakukubira okumanya oba oyagala nzijje twogele.

e) Kikikyenafuna mu?
Okunonyereza kujja kutuyamba okukyusa obujjajambi obuwebwa abalwadde nga owuwo okuyamba embeera y'o bulamu bwabwe ebere nugi. Tusubira nti kina kuyamba okogera kuumulwadde wo nga bangi bagamba bwebakyogerako bawulira nga kibayambye.

f) Okwetaba mu kwange kunbeera kwa nkisso?
Yee. Erinyaa lyo ne namba yasimu siyina muntu yenna gwengenda kubiwaa. Bwetunaba twogela kulutambi erinnya lyo sijja kulyogela era erinnya lino lyo njaku liwandika kulupapula lwawuffu wamu n'egyobera nga tewali asobola kumanya ki kyoyegedde. Byetukwata kulutambi njaku bisangula nga okunonyereza kunno kuwedde.

g) Ebinava mukunonyereza munabikola mutya?
Tujakuwandika alipooti mu butabo bwa baasawo basobole okumannya obujjanjabi bwa abalwadde nga owuwo bwe buyinza okulongosebwamu ne bye mwaliyagadde biberewo oba bikyuke.

h) Munakolaki bwe wanabbera wo omutawana
Tetusubira nti wanabeera wo omutawana gwonna nga wetabye mukonyerezza kunno kubanga tugenda kwogera bwogezzi era tetutadeewo ntekanteka yonna eyokusasula muntu yenna. Byonoba ofunye enyiike eyamanyi okuva mukwogera kunno ku mulwadde wo nja kuwerezza ewabakuggu bakuyambe era bwoba olina okwemulugunya kwonna okunonyreza nga kutandise kubira esimu sentebe wa kakiko

akalaba nti okunonyereza okwabulingeri mu dwalilo lye Mulago kugenda bulungi ye Dr. Nakwagala ku siimu 0782119498

i) Ani atekateka okunonyerezza kunno?
Nze tekakateka okunoyerezza kunno ngabwe nagambye nti ndi kumisomo gyange egya PhD nga nyambibwaako abasomesa bange abava mu tendekero lya univasite eya Edinburgh ebulaya ne Makerere University.

j) Okumannya ebisingawo
Bwoba oyagala okumannya ebisingawo kukunonyerza kunno nga tonasalawo kuba esimu yange Elizabeth Namukwaya number 0772595672.

Webale nnyo okutwala obudde bunno okusoma binno, nkubira esimu bwoba olina ekibuzo kyonna

Okusaba olukusa olwokwetaba mukunonyereza kunno. (yamujanjabi)

Omutwe: Ebyetagiisa mu kulongosamu mu bujjanjabi bwa abalwadde bo mutima mu dwaliro ly'e Mulago.
Omunonyerezi: Elizabeth Namukwaya

		Tekawo akabonero akagolola bwobakirizza
1.	Nkakasa nti nsomye nentegeera ebikwata ku kunnyereza kunno n'embuzza n'ebibuuzo	
.2.	Ntegedde nti okwetaba mukunonyerezza kunno no kwogera ku biffa kumulwadde wange kwa kyeyagalile, era nsobola okuvamu kunonyerzza kunno nga siwadde nsonga. Kinno tekijja kukosa bujajjambi bwamulwadde ne bwanayisibwa	
3.	Nzikiiriza byetwogera okubiteeka kulutambi era ntegedde nti bwe banabiwandika kulupapula tekujakubelako kilaga nti nze nabyogela. Bwe nayagala nsobola okusaba byebawandise ne mbisoma okukukasa nti bituufu	
4.	Nzikiriiza okutereka ebyo ebinaba biwandikidwa kasita erinnya lyange obe ekilaga nti nze nabyogela banaba babijeko	
5.	Njagala bampe kulipota enava mukunonyereza kunno	
6.	Nzikiiriza nti byenjogedde babiwandike nu butabo bwabasawo naye bajje ko erinnya lyange oba kyonna ekilaga nti nze eyayogela	
7.	Nzikiriza okwetaba mukunonyereza kunno	

---------- ---------- ----------
erinya lyo mwetabi omukono enaku z'omwezi

---------- ---------- ----------
erinya lya munonyerezi omukono enaku z'omwezi

Appendix Six: Topic guide for patients and health professionals

The Topic guide given here below is a list of potential questions and areas which will be explored in the interview but it will not be used prescriptively. The interview will be guided largely by the responses from the participants.

TOPIC GUIDE –PATIENTS

Thank you for accepting to participate in this study. I am here to listen to your life story since your illness started. I am not looking for any particular answers please feel free to say anything that you feel is important to you and please take your time. With your permission I shall come back after sometime to hear more about your illness story.

1. Tell me about your life (socio-demographics)

Prompts

- Age, Occupation, family, friends, address.

2. Tell me how your illness started (probably physical issues)

Prompts

- How did you notice there was something wrong? What events lead to this?
- How bad was it?
- When did you first notice that it was serious and how? (when noticed any of the following symptoms of difficulty in breathing when you lie flat, profound fatigue with exertion, generalised weakness and inability to exercise?)
- What did it mean to you?
- How did you feel?
- What did you do? And why? Any one influenced your actions? How did they do it?
- Any other associated problems then? (co-morbidity)
- How have the above problems changed over time?

3. What happened next? (diagnosis story)

Prompts

- Tell me about the process by which your condition was determined?
- How and what did you feel when you were first told you had heart failure?
- How has this knowledge changed your life if at all?

4. What was going on in your life then? (social)

Prompts

- How has life changed if at all and why? When did the changes occur ? What lead to the changes?
- How do you manage to live with the illness? How are you able to meet your day to day needs? Who has been most helpful to you during this time? And how?
- Tell me about your relationship with other people? Family, friends , neighbours. Has this changed? If at all why?
- How would you describe the kind of person you were before the illness and now? What contributed to this change?
- Could you describe a typical good day for you? Before the illness and after
- Could you describe a typical bad day for you? What contributes to this?

5. How if at all, have your thoughts and feelings about yourself changed since it all started? (psychological)

Prompts

- What positive changes have occurred in your life since then?
- What negative changes if, any have occurred in your life since then?
- As you look back, are there any other events that stand out in your mind? Could you describe each one? How did this event affect how what happened? How did you respond to it?
- Tell me about the most important lessons you have learned through this illness?

6. What helps you manage or go on? (coping and spiritual)

Prompts

- What gives meaning to your life in this condition? Has this changed compared to past and how?
- What is your source of strength, hope, peace? What strengths you have discovered?
- Do you ever ask yourself why me? When and why?
- What do you most value about yourself now? What do others value in you?

7. . How do you explain your condition? Tell me what you understand of your illness.

Prompts

- Where have you got information on your illness? Who gave it?
- How much information would you have liked to get? How much have you got so far? Why didn't you get what you needed?
- Which information is important to you and why?
- How would you like this information to be given?

8. Tell me about your care and treatment?

Prompts

- What is it like to make routine visits for medical care?
- How do you access treatment? What process do you have to go through to get treatment?
- What is your opinion on the treatment used? How does it help if at all? What do you expect from the treatment?
- Do you have any concerns about the treatment? What is it like to have to take drugs every day? Any problems and why? What helps with this if anything? What hinders it? How do you manage the medications?
- How do you care for yourself? Why? What helps with this? What hinders this?
- What is your relationship with the health professionals? How do they appear to you?
- What do you expect from a hospital visit/ admission? What do you expect from care? What would you like care for heart failure patients to be like?
- What leads to your change in condition to necessitate admission?

9. After these experiences what advice would you give to someone who has just discovered they have this condition?

Prompts

- Is there anything else you think I should know?
- Is there anything you would like to ask me?

Thank you for your time.

Interview guide for health professionals

1. Tell me about your experience in caring for patients with advanced heart failure? What is going well? What are the challenges?

2. In your experience, what is the typical clinical course of patients who have stage 4 heart failure?
    - How does the level of functioning change over the illness course?
    - How do symptoms change over time?
    - How often are they admitted to hospital? How often would they come to the outpatient clinic?
    - What are the reasons for readmission? If admitted in worse clinical state what are the reasons for this?
    - How does death usually happen?
    - What do you think is the average survival of these patients?

3. In your opinion, what are the common needs and concerns of patients with advanced heart failure?
    - What are the physical needs? What are the symptoms?
    - What are the social needs if any? How do these change over time?
    - What are the psychological needs if any? How do they change in the course of the illness?
    - What are the spiritual needs if any? How do they change in the illness course?
    - What are the information needs if any? How do these change over the illness course?

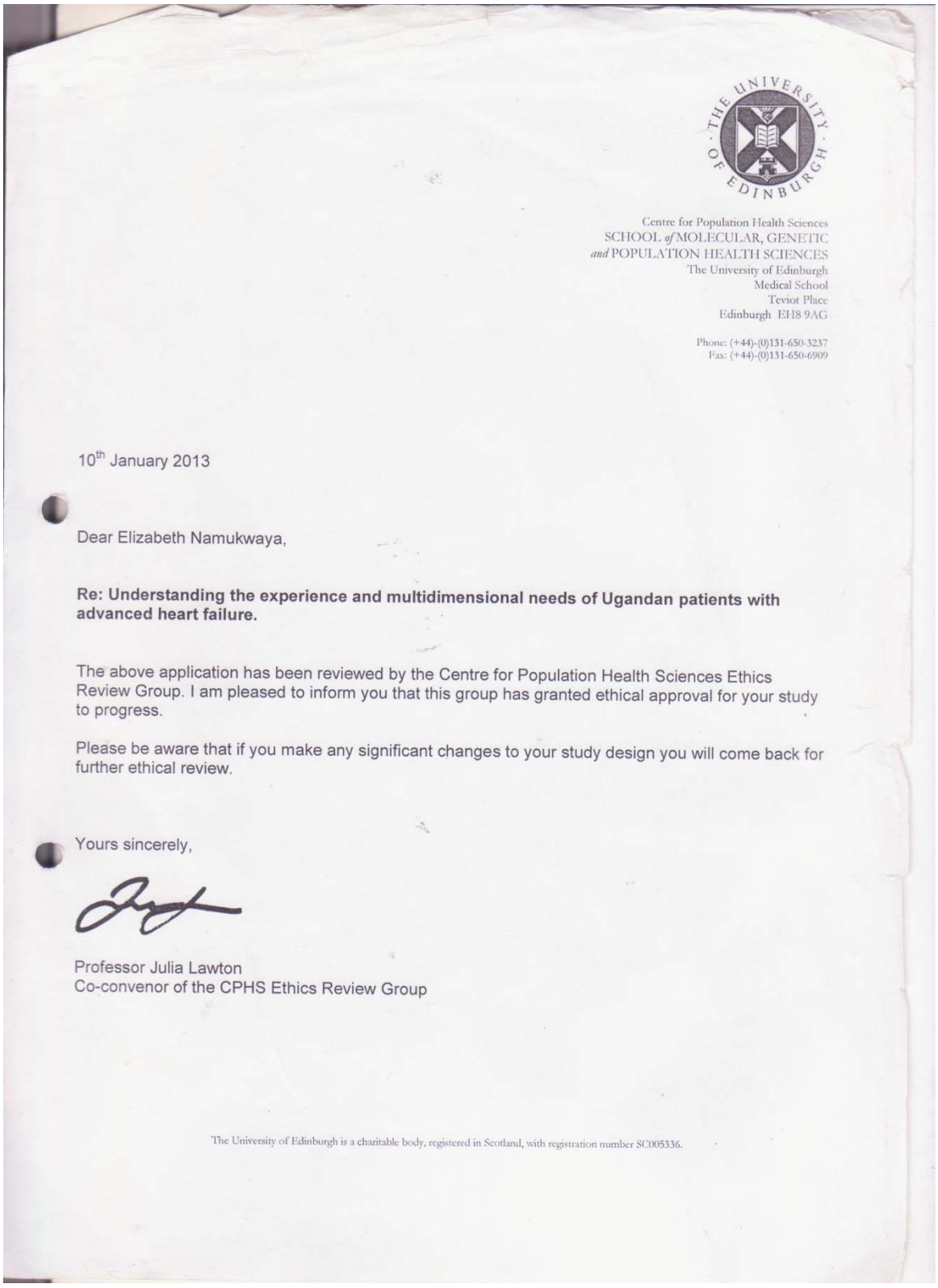
4. How are the patients' needs mentioned above being currently met?
    - What services are available? (diagnostics, medications, surgery, social work, spiritual support, information) how accessible are these to patients?
    - If not being met what are the reasons for this?

5. In your opinion what would be the best way to care for heart failure patients?
    - What resources are needed?
    - What would constitute a good model of care?

6. To add questions informed by patients' interviews

Thank you for time

Appendix Seven: Ethics approval letters



Centre for Population Health Sciences
SCHOOL *of* MOLECULAR, GENETIC
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The University of Edinburgh
Medical School
Teviot Place
Edinburgh EH8 9AG

Phone: (+44)-(0)131-650-3237
Fax: (+44)-(0)131-650-6909

10th January 2013

Dear Elizabeth Namukwaya,

Re: Understanding the experience and multidimensional needs of Ugandan patients with advanced heart failure.

The above application has been reviewed by the Centre for Population Health Sciences Ethics Review Group. I am pleased to inform you that this group has granted ethical approval for your study to progress.

Please be aware that if you make any significant changes to your study design you will come back for further ethical review.

Yours sincerely,

Professor Julia Lawton
Co-convenor of the CPHS Ethics Review Group

The University of Edinburgh is a charitable body, registered in Scotland, with registration number SC005336.

original.

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FAX: +256-414-532591
E-mail: admin@mulago.or.ug
Website: www.mulago.or.ug

IN ANY CORRESPONDENCE ON THIS SUBJECT PLEASE QUOTE NO.....

THE REPUBLIC OF UGANDA

MULAGO HOSPITAL COMPLEX
P. O. Box 7051
KAMPALA, UGANDA

25th February, 2013

Dr. Namukwaya Elizabeth
Principal Investigator

Dear Dr. Namukwaya

RE: APPROVAL OF PROTOCOL MREC: 313: UNDERSTANDING THE EXPERIENCE AND MULTIDIMENSIONAL NEEDS OF UGANDA PATIENTS WITH ADVANCED HEART FAILURE.

The Mulago Hospital Research and Ethics Committee at its meeting held on 21st February, 2013 reviewed your proposal referenced above and hereby grant approval for the conduct of this Studyfor a period of one (1) year from 21st February 2013 to 21st February, 2014.

This approval is subject to the following conditions:

1. That you will abide by the regulations governing research in the country as set by the Ugandan National Council for Science and Technology including abiding to all reporting requirements for serious adverse events, unanticipated events and protocol violations.
2. That you will submit this approved protocol and all accompanying documents for approval to UNCST before starting the study. In case of studies involving drug and medical devices, approval must be obtained from the National Drug Authority before starting the study.
3. That you will obtain administrative clearance from the office of the Deputy Executive Director before starting activities in any department of Mulago hospital.
4. That no changes to the protocol and study documents will be implemented until they are reviewed and approved by the Mulago Research and Ethics Committee.
5. That you provide annual progressive reports and request for renewal of approval at least 6o days before expiry of the current approval.
6. That you provide an end of study report upon completion of the study including a summary of the results and any publications.

I wish you the best in this Endeavour.

APPROVED
APPROVAL DATE EXPIRY DATE
21 FEB 2013 21 FEB 2014
MULAGO RESEARCH ETHICS COMMITTEE
IRC

DR. NAKWAGALA FREDERICK NELSON
CHAIRMAN MULAGO RESEARCH & ETHICS COMMITTEE

TELEPHONE: +256-414-554008/1
FAX: +256-414-5325591
E-mail: admin@mulago.or.ug
Website: www.mulago.or.ug

IN ANY CORRESPONDENCE ON THIS SUBJECT PLEASE QUOTES NO...

MULAGO NATIONAL REFERRAL HOSPITAL
P.O. Box 7051
KAMPALA, UGANDA

THE REPUBLIC OF UGANDA

Ref: **D/GC/178**

6th March 2013

The In-Charge,
Ward 4C

Re: Dr. Namukwaya Elizabeth

This is to introduce to you the above named who is doing a research on **"Understanding the experience and multidimensional needs of Uganda patients with advanced heart failure"** for a period of one (1) year.

The researcher is required to report back to this office with results and recommendations.

The researcher should produce this letter whenever required.

Thank you.

Dr. Birabwa-Male Doreen
Deputy Executive Director

Uganda National Council for Science and Technology

(Established by Act of Parliament of the Republic of Uganda)

Our Ref: SS 3083 **21st March 2013**

Elizabeth Namukwaya
Department of Medicine
Makerere University
Kampala

Dear Ms. Namukwaya,

RE: UNDERSTANDING THE EXPERIENCE AND MULTIDIMENSIONAL NEEDS OF UGANDAN PATIENTS WITH ADVANCED HEART FAILURE (SS 3083)

This is to notify you that the Uganda National Council for Science and Technology (UNCST) approved the above protocol on **21 March 2013**.

The approval is subject to the following condition:

1. Payment of the research administration and clearance fee of 50 US Dollar.
Payment is made to Standard Chartered Bank Speke Road Branch; the account title is UNCST and the account number is 8705611811400. If however you wish to pay in Uganda shillings, the account number is 0105610632101. If you intend to wire the research fees, the swift code is SCBLUGKA. Note that bank charges will entirely be the researcher's responsibility.

2. Obtaining of clearance to the study districts from the Research Secretariat, Office of the President; the process of obtaining clearance from the Research Secretariat, Office of the President is handled by UNCST on behalf of the researcher. Once approval has been secured, you will be notified.

Yours sincerely,

Hellen .N. Opolot
for: Executive Secretary
UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

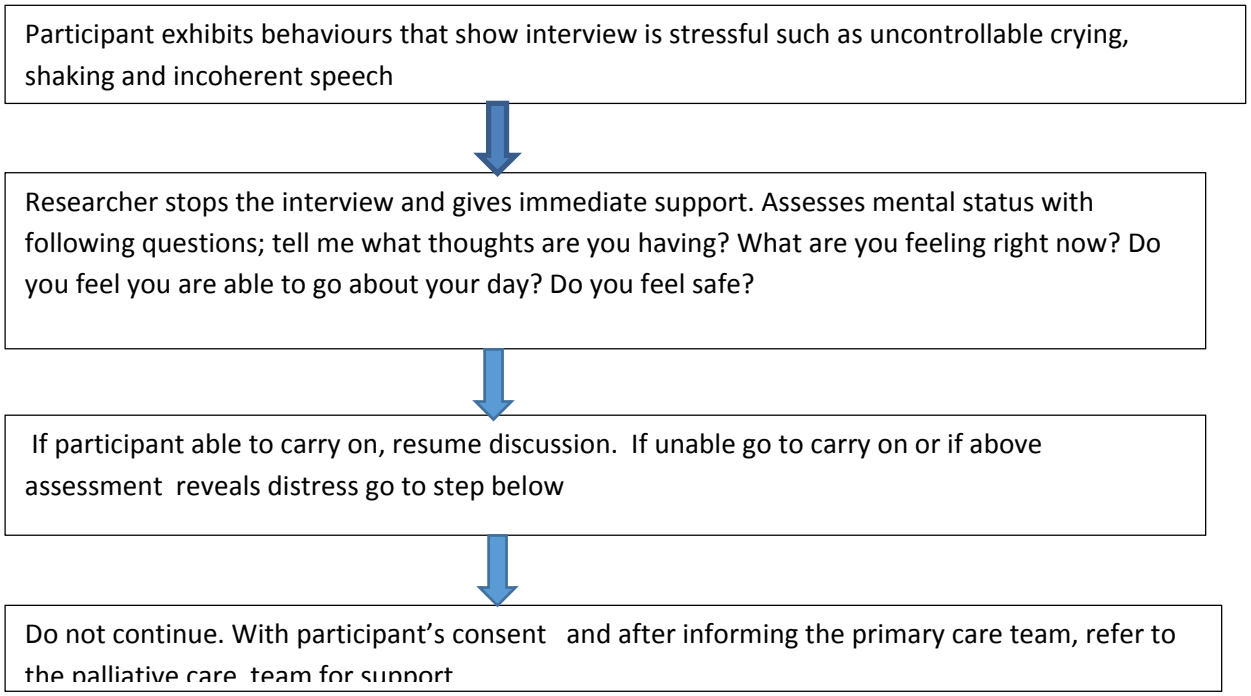
LOCATION/CORRESPONDENCE

Plot 6 Kimera Road, Ntinda
P. O. Box 6884
KAMPALA, UGANDA

COMMUNICATION

TEL: (256) 414 705500
FAX: (256) 414-234579
EMAIL: info@uncst.go.ug
WEBSITE: http://www.uncst.go.ug

Distress protocol for patients



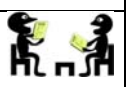
Appendix Eight: Summary of literature search and hits obtained from the different data bases

Data base	Total hits	Number Narrowed to and searched	Relevant	Repetitions	Non-english	Total taken
CINAHL	930	95	47	4	7	36
EMBASE	353	All 353 searched	26	6	4	16
psychINFO	582	159	17	6	3	8
MEDLINE	11179	62	39	17	2	20
Global health Library	32	All 32 searched	4	1	0	3
Global health	44	All 44 searched	5	0	3	2
Social care	606	390	13	5	0	8
	14071	**1135**	**151**	**39**	**19**	**93**

Details of the number of hits yielded for each search in each data base after narrowing down using qualitative inetrviews limiting to dates 2000-2015

Data base	HF and symptoms	HF and psychological	HFand social	HF and spiritual
CINAHL	38	14	23	20
EMBASE	322	12	16	3
PsychINFO	151	1	7	0
MEDLINE	26	23	8	5
Global health library	32	0	0	0
Global health	42	1	1	0
Social care	138	51	390	27

Appendix Nine: Diagram showing when serial qualitative interviews, phone contacts and deaths happened over the study period.

Patient 21		 2ND					
Patient 20			 2ND		 3RD		
Patient 19							
Patient 18			 2ND				
Patient 17							
Patient 16							
Patient 15							
Patient 14				Declined bereavement interview			
Patient 13				 2ND			 3RD
Patient 12		 2ND					
Patient 11							
Patient 10							
Patient 9			 2ND				

Patient 8		 2ND					
Patient 7				 2ND			 3RD
Patient 6			 2ND			 3RD	
Patient 5				 2ND			 3RD
Patient 4				 2ND			 3RD
Patient 3			 2ND				
Patient 2							
Patient 1				 2ND			
	1ST Interview	Month 1	Month2	Month 3	Month 4	Month 5	Month 6

Key :

 Phone call

 Face to face interview with patient and their carer

 Phone off

 Died

 Face to face interview with patient

 Bereavement interview

Appendix Ten: Nvivo coding framework

This is an example of a coding framework used during the 3rd interviews but it was developed from the first interview.

Nodes

Name	Sources	Referenc	Created On	Created
being healthy before ilness	1	1	19/07/2013 15	EN
being referred-fo	1	1	30/01/2014 10	EN
reason for referral	1	1	17/02/2014 10	EN
referral pathways	13	28	15/07/2013 10	EN
follow up	13	17	15/07/2013 11	EN
lay referral systems	1	1	19/07/2013 10	EN
level of hospital	2	2	15/07/2013 10	EN
services at other centers	2	3	23/07/2013 16	EN
coping with illness-fo	3	4	15/07/2013 11	EN
accepting the inevitable	1	1	18/07/2013 10	EN
being predestined	1	1	22/08/2013 15	EN
biographical reenforcement	1	2	18/07/2013 10	EN
facing illness	1	1	01/10/2013 11	EN
comparing with worse illness	2	2	18/07/2013 11	EN
having an attitude of gratitude	1	1	30/01/2014 14	EN
feeling gratitude for positive	4	4	17/07/2013 13	EN
having destructions	1	1	18/07/2013 11	EN
identifying with those who have suffered and overcome	1	1	17/07/2013 15	EN
letting go	2	6	19/07/2013 15	EN
living in hope	2	4	16/07/2013 16	EN
realising they are not alone	6	7	16/07/2013 16	EN
sharing problems with others	3	3	17/07/2013 11	EN
source of hope and strength	14	19	15/07/2013 11	EN
supporting realtionships	1	1	17/02/2014 22	EN
surrendering to God	4	6	15/07/2013 11	EN
course of illness-fo	2	4	15/07/2013 11	EN
disease stable	2	3	23/07/2013 12	EN
progressing disease	13	21	15/07/2013 10	EN
starting of illness (Nodes)	15	21	15/07/2013 10	EN
experience of health services-fo	5	8	18/07/2013 09	EN
experience of hospitalisation	11	23	15/07/2013 10	EN
reason for worrying	1	1	03/10/2013 10	EN
feeling of constant struggle with illness	1	1	17/02/2014 19	EN
feeling worried and emotional pain-fo	7	12	16/07/2013 15	EN
consequences of poor Hp patient relationship	1	1	22/08/2013 15	EN
feeing sad	9	13	16/07/2013 14	EN
feeling bad about being dependant	1	1	22/07/2013 16	EN
feeling sad about loss of function	1	1	22/08/2013 15	EN
feeling scared	1	1	17/02/2014 11	EN
feeling that life is not worthwhile	1	1	17/07/2013 14	EN
having other worries	1	1	19/07/2013 14	EN

Nodes

Name	Sources	Referenc	Created On	Created
having psychological needs	2	3	17/07/2013 14	EN
suffering	2	2	17/07/2013 14	EN
worrying about dying	2	2	16/07/2013 12	EN
worrying about future	8	12	16/07/2013 14	EN
getting hospitalised- fo	1	1	30/01/2014 10	EN
being hospitalised	12	20	15/07/2013 10	EN
interpreting illness in the spiritual context(spiritual narratives	13	17	15/07/2013 11	EN
explaining or understanding of illness in the spiritual di	4	7	16/07/2013 15	EN
failing God's test	1	1	18/07/2013 16	EN
God's role	13	19	31/01/2014 15	EN
why not me	1	1	18/07/2013 11	EN
living with loss-fo	3	4	16/07/2013 11	EN
failing to care for family	2	2	17/07/2013 12	EN
leaving school	1	2	23/07/2013 11	EN
losing a job	2	3	22/07/2013 09	EN
losing ability to work	4	4	15/07/2013 11	EN
losing control	1	2	22/07/2013 17	EN
losing family resources	2	3	17/07/2013 13	EN
losing income	4	5	15/07/2013 11	EN
losing life dreams	2	6	17/07/2013 14	EN
loss of family relationships	1	1	16/09/2013 20	EN
wishing to continue school	2	2	16/07/2013 14	EN
realising gravity of problem	1	1	22/08/2013 15	EN
recognizing advanced illness	1	1	17/02/2014 15	EN
suffering of family-fo	1	1	17/07/2013 15	EN
being isolated from parent	1	1	17/02/2014 10	EN
disrupting family plans	3	3	18/07/2013 15	EN
suffering family	4	4	22/07/2013 16	EN
supporting organisations in the community	1	1	17/02/2014 21	EN
beginning of the problem (Nodes)-fo	2	4	30/01/2014 10	EN
beginning of the problem	2	3	30/01/2014 10	EN
caring for self-fo	14	24	15/07/2013 12	EN
changing body image	2	2	16/07/2013 14	EN
changing level of functioning-fo	15	31	16/07/2013 14	EN
defining value in illness-fo	3	3	18/07/2013 14	EN
valuing life in comparison to things	1	1	19/07/2013 12	EN
experiencing periods of wellbeing or acceptable QOL- fo	9	9	15/07/2013 12	EN
getting added illness worsening well being	1	1	18/07/2013 10	EN
needing food to improve QOL	1	1	17/02/2014 22	EN
experiencing symptoms-fo	1	6	15/07/2013 10	EN

Nodes

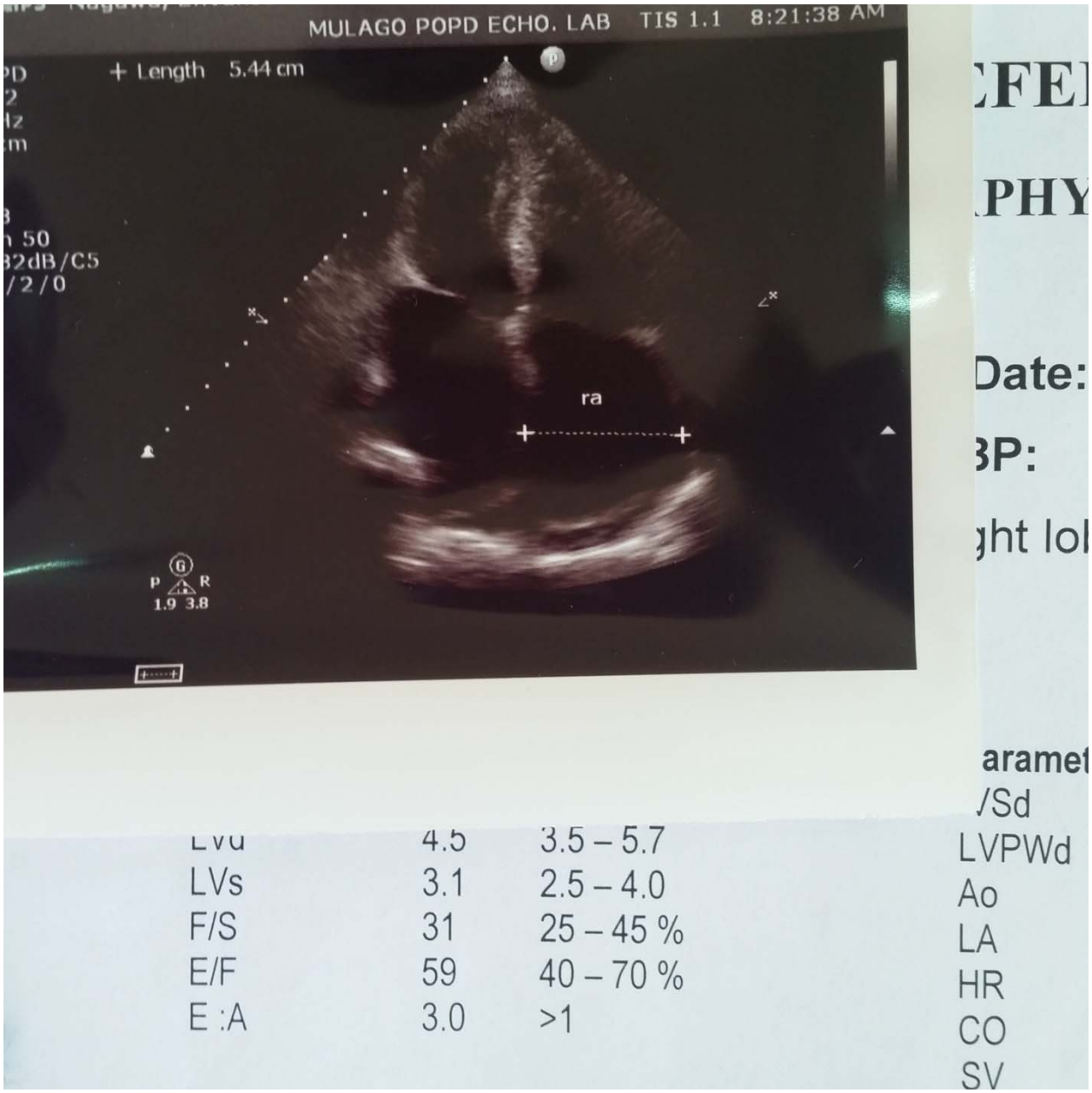
Name	Sources	Referenc	Created On	Created
beginning of the problem	16	29	15/07/2013 09	EN
activity causing symptoms	6	6	15/07/2013 09	EN
meaning of symptoms-	2	3	30/01/2014 11	EN
understanding of illness initially	15	29	15/07/2013 09	EN
recognizing illness	1	1	06/02/2014 10	EN
experiencing new symptom	14	39	15/07/2013 10	EN
pattern of symptoms with day and night (Nodes) (N	10	13	15/07/2013 10	EN
persisting symptoms	1	1	22/07/2013 14	EN
responding to symptoms	8	11	15/07/2013 10	EN
responding to the symptom	9	20	15/07/2013 09	EN
symptom course	2	2	06/02/2014 11	EN
worsening condition	1	2	17/02/2014 15	EN
Facing financial constraints	12	26	15/07/2013 11	EN
managing financial constarints	1	2	30/01/2014 13	EN
managing within financial constraints	5	7	15/07/2013 11	EN
failing system-fo	8	19	15/07/2013 10	EN
services offered in low hospital	3	5	15/07/2013 10	EN
getting information on what worsens condition	1	1	17/02/2014 15	EN
lay perspectives or beliefs-fo	11	25	15/07/2013 11	EN
being labeled with stigmatizing illness	4	4	16/07/2013 14	EN
suspecting witch craft	3	4	17/07/2013 15	EN
using alternative medicines	3	5	19/07/2013 15	EN
learning lessons-fo	12	13	16/07/2013 10	EN
life lessons	2	3	22/08/2013 15	EN
playing a role in your self care	1	1	18/07/2013 10	EN
living with cormobidities-fo	4	6	18/07/2013 09	EN
living with the illness	1	1	15/07/2013 12	EN
proposing ways of improving care-fo	7	12	16/07/2013 15	EN
Reaching a diagnosis-fo	1	1	15/07/2013 11	EN
being evaluated	16	32	15/07/2013 10	EN
delaying diagnosis	2	2	18/07/2013 14	EN
failing to diagnose	3	7	15/07/2013 10	EN
feeling desperate	1	1	17/07/2013 13	EN
getting wrong treatment	1	1	18/07/2013 14	EN
misdiagnosis	3	5	15/07/2013 10	EN
receiving treatment-fo	16	61	15/07/2013 10	EN
experience of treatment	1	2	31/01/2014 10	EN
using tradional or alternative medicines	7	10	22/07/2013 13	EN
views , knowlege and expectations of treatment	8	13	16/07/2013 16	EN

Nodes

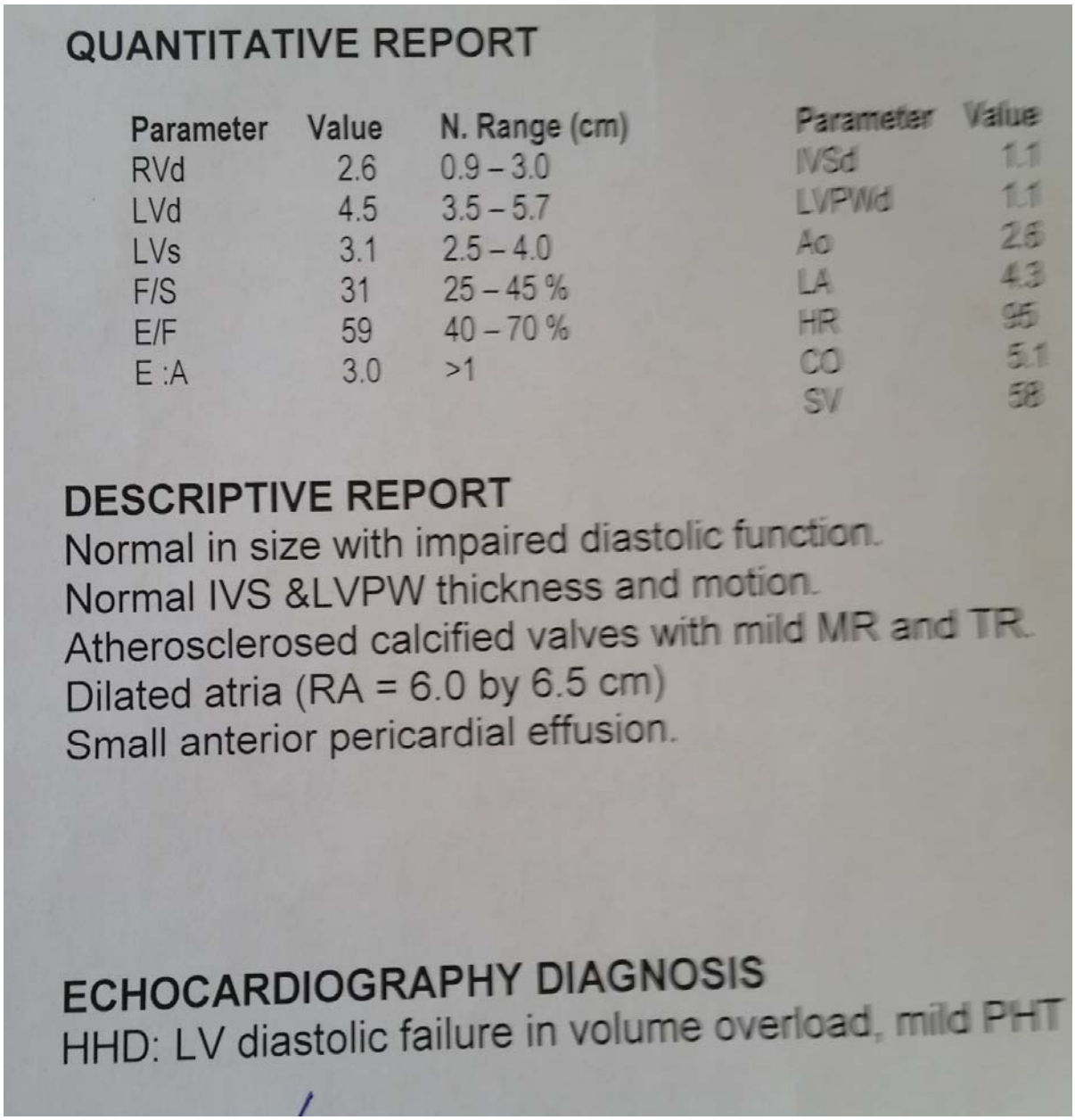
Name	Sources	Referenc	Created On	Created
relating with HPs-fo	1	1	30/01/2014 11	EN
expectactions of a health professional-fo	11	19	15/07/2013 12	EN
view of helath professionals and other staff	17	31	15/07/2013 12	EN
relating with others-fo	1	1	15/07/2013 16	EN
anticipating rejection	2	2	17/07/2013 10	EN
being devalued	2	2	17/07/2013 14	EN
being isolated due to diet	1	1	19/07/2013 12	EN
being stigmatized	1	1	18/07/2013 10	EN
being treated inhumanely	1	1	22/07/2013 16	EN
being unable to attend social and spirirtual events	2	2	15/07/2013 11	EN
burdening others	4	5	18/07/2013 15	EN
expectations from relatives and community	1	1	30/01/2014 14	EN
facing rejection	4	7	22/07/2013 09	EN
helping relationships	6	9	15/07/2013 11	EN
isolated form social groups	4	4	15/07/2013 11	EN
maintaining relationships	6	12	15/07/2013 11	EN
relating with spouse	1	1	17/02/2014 15	EN
seeking care	12	16	06/02/2014 16	EN
seeking care	2	2	22/08/2013 13	EN
tigger for seeking medical care	12	16	15/07/2013 10	EN
sharing information	19	179	15/07/2013 15	EN
being confused by conflicting nformation	3	4	18/07/2013 15	EN
importance of information	6	10	15/07/2013 11	EN
information gap	13	29	15/07/2013 10	EN
information given	18	59	15/07/2013 10	EN
information needs	19	31	15/07/2013 11	EN
keeping medical documents	3	3	19/07/2013 10	EN
negotiating treatment with Hps	1	1	17/02/2014 15	EN
opinion on getting bad medical news	10	16	15/07/2013 11	EN
responding to information	14	20	16/07/2013 13	EN
source of information	4	4	15/07/2013 12	EN
social context-fo	17	34	15/07/2013 11	EN
diffiucult social circurmstances	6	7	22/07/2013 09	EN
family	13	20	15/07/2013 11	EN
sitting at home before illness	1	1	22/08/2013 13	EN
The heart is in water.	1	1	15/07/2013 14	EN
understanding of illness-fo	9	16	15/07/2013 11	EN
current undesrstanding of illness(Nodes)	10	28	15/07/2013 10	EN
current undesrstanding of illness-fo	1	1	30/01/2014 11	EN
intermittent symptoms hindering understanding	2	2	15/07/2013 10	EN

Appendix Eleven: Images from the study

An echocardiogram picture from one of the patients



An Echocardiogram report from the same patient



QUANTITATIVE REPORT

Parameter	Value	N. Range (cm)
RVd	2.6	0.9 – 3.0
LVd	4.5	3.5 – 5.7
LVs	3.1	2.5 – 4.0
F/S	31	25 – 45 %
E/F	59	40 – 70 %
E :A	3.0	>1

Parameter	Value
IVSd	1.1
LVPWd	1.1
Ao	2.6
LA	4.3
HR	95
CO	5.1
SV	58

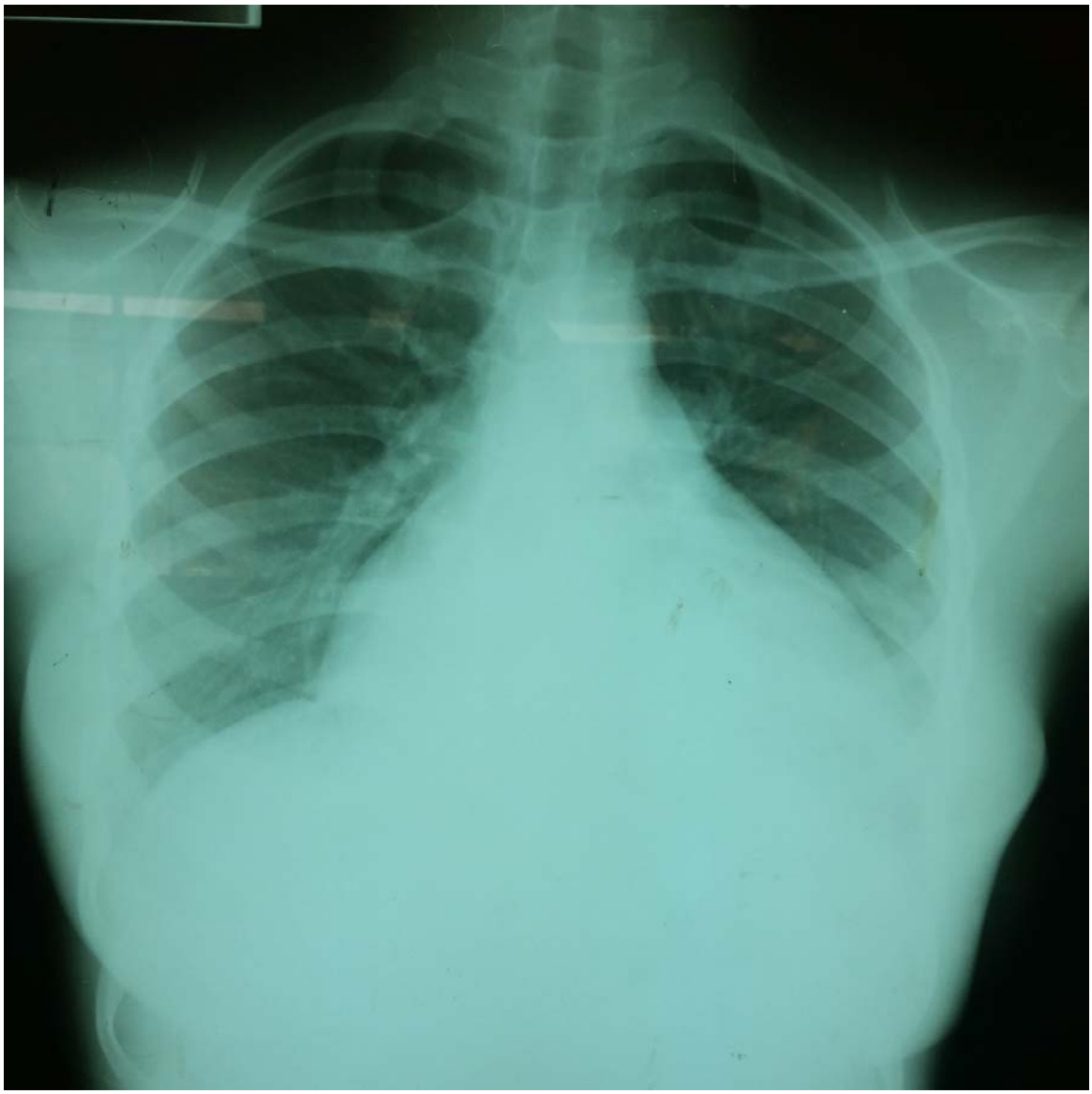
DESCRIPTIVE REPORT

Normal in size with impaired diastolic function.
Normal IVS &LVPW thickness and motion.
Atherosclerosed calcified valves with mild MR and TR.
Dilated atria (RA = 6.0 by 6.5 cm)
Small anterior pericardial effusion.

ECHOCARDIOGRAPHY DIAGNOSIS

HHD: LV diastolic failure in volume overload, mild PHT

Chest radiograph of patient with heart failure



Picture of one of the patient's home

Appendix Twelve: Work that has been disseminated from this study

Living with advanced heart failure in Uganda

Elizabeth Namukwaya[1,2], Scott Murray[1], Mhoira Leng[1,2], Julia Downing[2], Liz Grant[1]
[1] Primary Palliative Care Research group, University of Edinburgh,
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Background

Non communicable diseases such as heart failure are increasingly prevalent in Africa. Literature from high income countries revealed that patients with heart failure have multidimensional needs. However little information exists from the African setting where the social context is different and care is predominantly based on a biomedical model, with palliative care being mainly for HIV and cancer patients.

Objective

To understand the experiences, needs and use of services for patients with advanced heart failure Uganda.

Methods

Serial longitudinal in-depth qualitative interviews using the grounded theory approach were conducted with 21 adults with advanced heart failure admitted in Mulago (a tertiary referral) hospital in 2013. Patients were purposively selected to include various aetiologies and ages. Data from the first interviews are included here.

Results

Six major themes were identified in the heart failure experience as below

- **Experiencing physical changes**

'I started by feeling burning in the chest center when I had gone to dig, when I would strike the ground with the hoe I would feel a lot of burning inside my chest. I had to hold here, I would press the chest a lot and it would go but come back when I dig' (patient 1)

Experiencing psychological problems

'This time I am very worried and as you see I have lost a lot weight. My condition now seems to be very bad' (patient 5)

- **Experience of lacking information**

'The problem is that we are not told by doctors what to do, what to eat .. after they check you they just write medications for you but you do not know what to do' (patient 16)

- **Experiencing social changes**

'I was working in a bar but I was told that I should not return but look for another job. Hmn, because I am always sick'(patient 12)

- **Experiencing existential/ spiritual issues**

' I said to God after all I have been through is this what You choose to pay me with? Is this the time you decide to give me this?'(patient 20)

- **Experience with health care**

'We have to buy some medications, ever since I came to the ward ,I had not got any dose, not until I had to buy the medicines, but also most times when we come to the clinic there are no medications.' (patient 5)

Conclusion

The patient experience of heart failure in Uganda is one of high symptom load, lack of information, social problems and sometimes existential distress. Medications are expensive if available. Health and social services responsive to these many dimensions of need must be developed and made available in local health care and hospitals.

"It's when I could no longer work that I decided to go to hospital": Patients' experiences of coming to a diagnosis of heart failure in Uganda

Elizabeth Namukwaya[1,2], Liz Grant [1], Mhoira Leng[1,2], Julia Downing[2], Scott Murray[1]
1. Primary Palliative Care Research group, University of Edinburgh, 2. Palliative Care Unit, Makerere University and Mulago hospital, Uganda, liznam2002@yahoo.co.uk

Background

Cardiovascular diseases, e.g heart failure, are increasingly prevalent in low income countries such as Uganda[1]. Interventions such as use of drugs with a mortality benefit, and timely palliative care, improve outcomes for patients with heart failure. However, in Uganda patients with heart failure are often diagnosed in advanced stages of the illness.[2] have a short intervention period and often die before they benefit from these interventions.

Objectives

We aimed to understand Ugandan patients' experiences of coming to a diagnosis of heart failure and factors determining delayed diagnosis

Methods

Patients with heart failure in Mulago hospital in Uganda were recruited, and serial in-depth qualitative interviews conducted. Purposive sampling was used until thematic saturation was achieved at a sample size of 21 participants.

Results

Six themes were identified

Heavy symptom and psychosocial burden

'I used to feel easily tired on walking, when I lay flat I could not breathe well, I was coughing. Before that started I used to bend and was able to do some work like chopping wood but now I could no longer be able to do such work. Then the abdomen started swelling and it felt hot inside . And because of this I would not sleep. Now I cannot help myself, my mother cares for me I wake up and go and sit, , then sleep, I cannot even bend, I cannot not even bathe myself she bathes me ***(patient 14)***

Having insufficient information on diagnosis

'They have done several scans but have not explained to us the results they did not explain to me the echo too.' ***(patient8)***

Delay in seeking care

'I just went on with my duties as usual until I felt worse, I could no longer work I also felt chest pain, I could not carry things I used to carry I used to get difficulty in breathing then I decided to go to hospital" ***(patient 3)***

"I have had the problem for long but tried to push on, you know for us when we get ill we start with using local herbs , but then I started having palpitations and sweating , then I felt my abdomen was distending and then I went to a clinic" ***(patient 10)***

Protracted period of assessment

'I went to several clinics, wherever I went I was told to submit sputum so that they can look for the disease but whenever they checked they failed to find what disease it was until a year later' ***(patient 15)***

Slow and convoluted referral system

'I started in Nkozi hospital they wrote a referral for me to go to Gombe hospital and when I got there they took Xrays of me and then told me they were unable to manage my illness and referred me on to Mulago hospital'. ***(patient 19)***

Health system factors leading to late diagnosis

'They asked me for a chest X-ray but at Nakaseke but the machine there was out of function, so they referred me to Lacho.' ***(patient 5)***

Conclusion

Health service barriers including poor resourcing and limited skills, coupled with patient inability to accurately self-assess life threatening illness delayed diagnosis of heart failure. These need to be addressed in tandem for patients to benefit from drug and palliative care interventions for better outcomes.

References

1. J.K. Kuule, E. Seremba, and J. Freers, 'Anaemia among Patients with Congestive Cardiac Failure in Uganda: Its Impact on Treatment Outcomes', SAMJ: , 99 (2009), 876-80
2. N. Ntusi, and B.M. Mayosi, 'Epidemiology of Heart Failure in Sub-Saharan Africa', Expert review of cardiovascular therapy, 7 (2009), 169-80